

The Effects of a Therapeutic Recreation Program on Overall Well-being Among Older-  
adults with Alzheimer Disease and Their Care Partner

Laura Rolph, BRLS

Submitted in partial fulfillment of the requirements for the degree  
Master of Arts in Applied Health Sciences  
(Leisure Studies)

Faculty of Applied Health Sciences  
Brock University  
St. Catharines, ON

© April 2017

**Abstract**

**Background:** With the increased pressures that our aging population has on our country, this study looks at the effects that an 8 week Therapeutic Recreation infused program has on the well-being for both individuals with Alzheimer Disease and their Care Partner.

**Method:** Sample of the study is from a single secondary data set. Sampling criteria for the study was individuals with early to mid-stage signs of Alzheimer Disease or other dementias and their Care Partner from across 6 different locations in Ontario, Canada. Pre and Post data from the Warwick-Edinburgh Mental Well-Being Scale was analyzed through a repeated measures ANOVA.

**Results:** Care Partners indicated an increase in well-being slightly higher than that of the Persons With Dementia. This slight increase in well-being was not statistically significant for either the Care Partner or the Person's with Dementia. Unexpected ANOVA findings revealed that there was a significant between-subject effect as Care Partners showed a higher overall level of well-being. This further emphasizes the importance for early intervention for Persons with Dementia.

## TR EFFECTS ON WELL-BEING

**Conclusion:** Overall this program is in the early stages of development. It is still believed that program modifications could facilitate a cost-effective intervention for communities.

## TR EFFECTS ON WELL-BEING

**ACKNOWLEDGEMENTS**

I would first like to take this time to thank my thesis advisor Dr. Suzie Lane at Brock University for her ongoing support and guidance over the years. There have been several personal and academic challenges that were faced throughout the years and Dr. Lane was always available to point me in the right direction, was patient and was able to instill the confidence that I needed. Dr. Lane, you are a strong mentor and without your support throughout this entire process, this accomplishment would not have been possible. Thank you!

Additionally, I would also like to thank and acknowledge my committee members, Dr. Colleen Hood, Dr. Sanghee Chun and my external reviewer Dr. Jerry Singleton. I am grateful for their valuable comments and feedback throughout this process.

I would like to thank the Alzheimer Society of Ontario for their commitment to improving the lives of those affected by Alzheimer Disease. Their commitment to innovative programming to address Alzheimer Disease in Ontario made this research project possible. I would also like to thank all of the ASO facilitators and volunteers that played a key role in the delivery of the Minds in Motion program.

Finally, I must express my profound gratitude to my parents, family and friends for providing me with unfailing support and encouragement throughout my years of study

## TR EFFECTS ON WELL-BEING

and through the process of research and writing this thesis. I have a handful of people that I am gratefully indebted to for their endless hours that they dedicated to making the program kits for all program locations. This accomplishment would not have been possible without them. Thank you!

## TABLE OF CONTENT

<b>ABSTRACT .....</b>	<b>ii</b>
<b>ACKNOWLEDGEMENTS .....</b>	<b>iii</b>
<b>TABLE OF CONTENT .....</b>	<b>vi</b>
<b>LIST OF TABLES .....</b>	
<b>LIST OF FIGURES .....</b>	
<b>LIST OF ABBREVIATIONS .....</b>	
<b>CHAPTER ONE: INTRODUCITON .....</b>	<b>1</b>
Need for Study .....	4
Statement of the Purpose .....	4
Research Question .....	5
Delimitations .....	5
Limitations .....	7
<b>CHAPTER TWO: LITERATURE REVIEW .....</b>	<b>8</b>
A Brief Overview of the Impact of Alzheimer’s Disease in Canada .....	8
Canada’s Overall Rising Issue .....	10
Healthcare system and economy .....	11
Family impact .....	12
Suggestions for moving forward .....	13
Prevention .....	14
Delay onset .....	14
Caregiver .....	14

## TR EFFECTS ON WELL-BEING

Assign a case manager .....	15
Community programs .....	15
Alzheimer's Disease – Steps Moving Forward .....	16
Alzheimer's Disease in Ontario .....	21
Therapeutic Recreation – Leisure and Well-being Model.....	36
Positive Emotion, Strengths and Well-Being through TR Programming .....	41
Secondary Research Analysis.....	45
Conclusion .....	46
<b>CHAPTER THREE: METHODS .....</b>	<b>48</b>
Participants .....	48
Minds in Motion (MiM) Program Procedures.....	49
Social Connectedness Program .....	50
Description of Test Instrument .....	52
Design of the Experiment .....	55
Treatment of Data .....	57
Conclusion .....	58
<b>CHAPTER FOUR: RESULTS AND DISCUSSION .....</b>	<b>59</b>
Results .....	59
Hypothesis Statement .....	59
Testing the Hypothesis .....	60
Person with dementia.....	60
Care partner.....	60

## TR EFFECTS ON WELL-BEING

Additional Findings .....	61
<b>CHAPTER FIVE: CONCLUSION .....</b>	<b>63</b>
Overview .....	63
Summary.....	64
Unpredicted Findings .....	65
Discussion.....	66
Participants.....	67
Facilitators .....	68
Community Based Research .....	70
Secondary Data .....	72
Measurement.....	74
Program Design .....	75
Lessons Learned .....	76
Recommendations .....	78
Conclusions .....	80
<b>REFERENCES.....</b>	<b>84</b>
<b>APPENDICES</b>	
A    Minds in Motion Flyer.....	91
B    Mins in Motion Registration Form .....	92
C    Ethics Approval – University of Waterloo .....	93
D    Ethics Approval – Brock University .....	94
E    Informed Consent.....	95



## TR EFFECTS ON WELL-BEING

F	Participant Consent to Participate in Evaluation of MiM .....	97
G	Warwick-Edinburgh Mental Well-being Scale .....	99
H	Participant Self-Assessment Questionnaire: Pre-Test .....	100
I	Participant Self-Assessment Questionnaire: Post-Test .....	102

## TR EFFECTS ON WELL-BEING

**List of Tables**

Table 1	Descriptive Statistics for WEMWBS Scores .....	60
---------	--	----

**List of Figures**

<i>Figure 1.</i> Within-Subject Mean Scores .....	62
---	----

## TR EFFECTS ON WELL-BEING

**List of Abbreviations**

AD.....Alzheimer's Disease

ASO.....Alzheimer's Society of Ontario

CP.....Care Partner

CIL.....Check in List

LWM.....Leisure and Well-being Model

MiM.....Minds in Motion

PWD.....Person with Dementia

TR.....Therapeutic Recreation

WEMWBS...Warwick Edinburgh Mental Well-Being Scale

## **Chapter 1**

### **Introduction**

It is predicted that over the span of 30 years (2008-2038) the cases of dementia will grow from an estimated 400,000 to more than double that by 2038 based on current trends (Public Health Agency of Canada, 2010). This growing increase of individuals living with Alzheimer's disease (AD) has and will continue to put a tremendous strain on those families, resources, health care needs and community support systems in Canada. Alzheimer's Disease (AD) is a mental health concern that impacts all aspects of an individual's life (Public Health Agency of Canada, 2010). Canada has now identified this as a growing concern for the country and has recently invested in the future by developing a National Strategic Plan (Ambrose, 2014). The Alzheimer Society of Canada (2015) continues to provide necessary services to meet the needs of this population and is working to improve current practice and research to progress the services that are available for families.

With this rapid increase of prevalence of AD, more pressures will be placed on a variety of resources, however, care partners (CP) and families will be the primary support system for an individual who experiences AD. The time that family members spend caring for a loved one with dementia could be affecting their paid work hours, the time that they spend focusing on their family, or their well-being. It is estimated that by 2040 families will be devoting "1.2 billion unpaid hours per year to support a family member with dementia" (Lowi-Young, 2014, p.3). With this knowledge, it is important to be

## TR EFFECTS ON WELL-BEING

aware of the supports that will need to be in place to assist the CP's of individuals with AD. There is currently no cure for AD. However, it is hopeful that through the use of evidence-based research there could be interventions developed to assist those living with the disease, their families, and our communities.

When exploring evidence-based research to assist with this growing crisis, it is important to explore options outside of medication. There are increasing amounts of research looking at the health benefits that positive emotion can have for improving individual well-being. Therapeutic Recreation (TR) is a field of practice that identifies the benefits that positive emotion can contribute to intervention approaches. Trugade, Fredrickson and Barrett (2004) identified a variety of advantages that can be gained from positive emotion. Some of these recognized benefits of positive emotion are improved ability to deal with stressful situations, lower hospital readmissions, improved health for individuals with cardiac disease, enhanced immune system functioning, longevity, improved social skills and relationships, increased emotional well-being and improved psychological health (Carruthers & Hood, 2007; Fredrickson, 2000; Fredrickson & Joiner, 2002; Trugade, et al., 2004; Hood & Carruthers, 2007, Weytens, Luminet, Verhofstadt, et al., 2014). From this, we can extrapolate that positive emotion has the potential to impact several domains. With this knowledge, this study has tried to determine if TR interventions focusing on the individuals' strengths will increase positive emotion and well-being to enhance the participants and their care partner's overall well-being. The logical progression of increasing positive emotion with the person with AD and their care partner (CP) is through experiencing happy moments with someone.

## TR EFFECTS ON WELL-BEING

A seven-week Therapeutic Recreation (TR) program utilizing the Leisure and Well-being Model (LWM) by Hood and Carruthers (2007) was used to implement this focus on positive emotion and well-being. This study aimed to increase the skills and resources for individuals with AD and their CP through various leisure opportunities designed to improve their positive emotion and well-being. Through participating in this TR program, it was anticipated that individuals would have the chance to participate in meaningful activities that would facilitate an opportunity for individuals to increase their positive emotion and well-being which can overall enhance their quality of life.

The purpose of this study was to identify the benefits of a TR intervention that utilizes the Leisure and Well-Being Model (LWM) for individuals with mild Alzheimer's disease (AD) and their care partners (CP) to create foundational knowledge on how to best benefit the quality of life for those living with AD and their CP. With this rapid increase of prevalence of AD, more pressures will be placed on a variety of resources, however, care partners (CP) and families will be the primary support system for an individual who experiences AD. As previously mentioned, dementia can have a significant affect on a variety of domains for family members caring for a loved one.

This study determined if TR is an approach that can be used to lessen the impact that this disease has on individuals who have AD and their CP. Through providing meaningful and positive focused programs, we can provide an opportunity for building skills and resources to support Canadians while they go through the experience of having a loved one progress through this disease.

## TR EFFECTS ON WELL-BEING

### **Need for Study**

There is currently no existing research that has been conducted on the role of utilizing the LWM (Carruthers & Hood, 2007; Hood & Carruthers, 2007) as an intervention tool to enhance well-being and overall quality of life in both individuals with AD as well as their CP. While there is limited research available that assesses the use of TR as an intervention for care partners or the individual with AD, there are no studies that currently evaluate the benefits that TR can contribute to intervention sessions that include both the individual with AD along with their CP.

Until now, the Alzheimer's Society of Ontario has not utilized evidence-based research regarding early intervention for individuals with AD to guide their practices. This study used evidence-based research to determine if using a TR intervention is a reasonable approach for this population in order to build skills that would increase positive emotion as well as enhance well-being among individuals with AD and their CP's. With Canada's aging population, there is more pressure on communities to take a proactive approach to preserving overall well-being (Prince, Bryce & Ferri, 2011; Public Health Agency of Canada, 2010). This research will assist with guiding and providing feedback and suggestions on interventions for moving forward with this population.

### **Statement of the purpose**

The purpose of the study is to examine an effect of a Therapeutic Recreation program on enhancing overall well-being for individuals with Alzheimer's Disease and their care partners.



## TR EFFECTS ON WELL-BEING

### Research Question

The overarching question is whether participants with Alzheimer's disease, and their care partners, have documented improvements in their wellbeing from the pre-test to the post-test as a result of participating in a therapeutic recreation program aimed at increasing skills and resources?

Questions to be addressed in this study:

- 1) Does participating in the seven-week TR program of Minds in Motion increase the well-being of participants with Alzheimer's Disease?
- 2) Does participating in the seven-week TR program of Minds in Motion increase the well-being of the care partners of the participants with Alzheimer's Disease?

The following hypothesis will be tested:

1. Persons with dementia (PWD) are expected to increase significantly in their well-being from pretest to posttest measurements.
2. Care Partners (CP) for individuals with AD are expected to increase significantly in their well-being from pretest to posttest measurements.

### Delimitations

This Study was delimited to the following:

1. Twelve programs offered in six different locations throughout Ontario: (a) Grey-Bruce, (b) Hamilton Halton, (c) Waterloo Wellington, (d) London-Middlesex, (e) Sudbury- Manitoulin and (f) Thunder Bay.

## TR EFFECTS ON WELL-BEING

2. Maximum of 11 individuals who were experiencing mild AD and their care partners per location per session (Care Partners can be anyone who is significant to the participant. A wife, child, grandchild, friend, etc.)
3. Measurement tool utilized was Warwick-Edinburg Mental Wellbeing Scale.
4. Staff implementing the program were trained at a workshop by the program developers. Further, follow-up and clarification was explained through emails and teleconferences.
5. The first group of programs were offered April – May 2014.
6. Each program ran for eight weeks. Seven of those weeks had specific TR programs (the final week was a social celebration).
7. A mixture of males and females in each group.
8. Each location was trained and provided with a manual and a tool kit to facilitate programs.
9. Weekly individual assessments were conducted to assess the effects of that particular program.
10. Facilitators provide feedback based on their experience of the session for future improvement.

## TR EFFECTS ON WELL-BEING

### **Limitations**

This study was limited by the following:

1. Certified Therapeutic Recreation Specialists are not facilitating the TR Sessions
2. Researchers are not on site collecting data to ensure a normalized environment.
3. Sampling – participant may have a care partner assist with surveys which could skew results
4. No pre-program testing were required of individuals in order ensure that participants are in fact in the early stages of AD. Requiring proof of AD onset could act as a barrier to participant involvement in the program.

## **Chapter 2**

### **Literature Review**

The following will allow the reader to review the literature that is relevant to the nature of this study. This chapter will start off with a brief overview of the impact of Alzheimer's disease in Canada. From there the chapter will be divided into four additional sections. The first section will discuss Canada's overall rising issue, which will be further separated into the following subsections: Healthcare system and economy, family impact, and suggestions for moving forward. When discussing 'suggestions for moving forward,' the section will be broken down into several key components. This chapter will then discuss the other three sections; Alzheimer's Association – steps moving forward and Ontario's approach, TR – Leisure and Well-being Model, and Positive emotions and Well-being through TR programming.

#### **A Brief Overview of the Impact of Alzheimer's Disease in Canada**

As Canada's population continues to age there are increasing challenges that Canada faces regarding the quality of life as well as health care costs (Public Health Agency of Canada, 2010). With an aging population, there exist growing numbers of individuals who are developing AD or other related dementias (Alzheimer Society of Canada, 2010). The Alzheimer Society of Canada (2010) identifies that unless we act now, this disease will have grave consequences for Canada. Many programs that are offered at the Alzheimer's Society of Ontario focus on individuals who are in the mid to later stages of Alzheimer's. These programs are critical to meet the needs of communities to assist in educating individuals with AD as well as their families on what

## TR EFFECTS ON WELL-BEING

to expect with the disease and the resources that are available to them. However, more recently, the Alzheimer's Society of Ontario has taken a new approach to focus programming towards individuals who are in the earlier stages of AD. There may not be a cure for AD, but through innovative interventions, it could be possible to slow or prevent the progression of the disease (Prince, Bryce & Ferri, 2011). Department of Health (2009) discusses how there is a definite misconception that nothing can be done to help people with dementia. However, the report goes on further to explore the benefits and implications of early diagnosis. Through attaining early diagnosis, people with dementia and their CP are afforded choices and can have the opportunity to seek treatment, care and support as, "contact often occurs late in the illness and/or crisis when opportunity for harm prevention and maximization of quality of life has passed" (Department of Health, 2009, 17). Due to this understanding, there is a new focus on earlier interventions for individuals who have mild symptoms of Alzheimer's disease.

Prince, et al. (2011) identify many non-pharmacological interventions that can be utilized for individuals with dementia. Some of these interventions include psychological, psychosocial and psychoeducational interventions, "with the potential to improve cognitive functioning, delay institutionalization, reduce caregiver strain and psychological morbidity and improve quality of life" (Prince, Bryce & Ferri, 2011, p.12). Therapeutic Recreation (TR) when utilizing the Leisure and Well-being model (LWM) is a person-centered intervention that uses individuals' strengths to further develop their skills and resources through the use of meaningful and intentional leisure interventions with a distal goal of increasing well-being through utilization of psychosocial and

## TR EFFECTS ON WELL-BEING

psychoeducational interventions (Hood & Carruthers, 2007). Well-being promotes and preserves growth in various domains of health such as physical, social, emotional, spiritual and cognitive abilities (Hood & Carruthers, 2007). Therapeutic Recreation interventions are designed to assist the individual with building their skills and resources to obtain optimal health and well-being. Improving the overall health and well-being of individuals with AD could decrease the financial stress that this subpopulation and their families place on the health care system (Alzheimer Society of Canada, 2010).

The purpose of this study is to identify the benefits of a TR intervention that utilizes the Leisure and Well-Being Model (LWM) for individuals with mild Alzheimer's disease (AD) and their care partners (CP) to create foundational knowledge on how to best benefit the quality of life for those living with AD and their CP. Initiatives like this can be used to learn from, build from and improve upon for other associations and communities to use. Understanding the role that TR plays in this process will dictate future programs that Alzheimer's societies offer to assist with our countries growing crisis.

### **Canada's Overall Rising Issue**

As of 2011, the Baby Boomers entered their senior years (65+), signaling the beginning of the acceleration of Canada's aging population. There has been a growing concern for the economic impact that this will have on the country. Alzheimer's Society of Canada (2010) has suggested that this acceleration in aging population, "will place a tremendous strain on Canada's capacity to provide essential health care services and community care as well as patient and caregiver support services, potentially

## TR EFFECTS ON WELL-BEING

overwhelming the country's health care system" (p. 10). The Alzheimer's Society of Canada published an article titled *Rising Tide: The impact of Dementia on Canadian Society* (2010) that identified that "if we do nothing, the number of Canadians with dementia in 2018 will be twice that of 2008" (Alzheimer's Society of Canada, 2010, foreword). This significant increase will cause several challenges for Canadian families, the healthcare system as well as the economy. Many countries have been taking a proactive approach to this growing concern and have developed a National Strategic Plan (Ambrose, 2014). Unfortunately, as of 2010, Canada had yet to develop their national plan, however, as of 2014, Canada's government announced that they had "joined our G7 partners and other global partners to address this growing challenge" (Ambrose, 2014, p. 1). The Alzheimer's Society of Canada has been working on addressing the concerns and challenges that this presents for our country, "the goal of the Rising Tide Project is to generate a reliable, evidence-based foundation upon which policymakers can build a comprehensive national plan" (Alzheimer's Society of Canada, 2010, p.2). In presenting the concerns that dementia and AD can cause for our population, it becomes clear that it will require federal, provincial and territorial governments to take action. To further understand the impact of AD in Canada, three subsections follow: Health care system and economy, family impact as well as suggestions for moving forward.

**Healthcare system and economy.** Alzheimer's disease is, "the most significant cause of disability among Canadians over the age of 65" (Alzheimer's Society of Canada, 2010, p. 2). As previously mentioned, it is clear that unless Canada prepares for these coming changes, that there is potential to overwhelm the countries health care system and

## TR EFFECTS ON WELL-BEING

economy. The “top 10 % of older Ontarians account for 60% of our annual spending on healthcare” while the “healthiest 50% of older people only take up 6% of overall spending” (Sinha, 2012, p.1). This emphasizes the importance of keeping older adults healthy to lessen the potential impact that this population could have on our country. “The total Economic Burden is expected to increase substantially from approximately \$15 billion in 2008 to \$153 billion by the year 2038 (in future dollars)” (Sinha, 2010, p.8). These statistics present current concerns with the health care system to meet these demands of this population. When discussing Ontario’s situation, it was identified that “if left unaddressed, our demographic challenge could bankrupt the province” (Sinha, 2012, p.2).

**Family impact.** Alzheimer’s disease puts a significant amount of pressure and burden on family members and care partners (CP) both emotionally and financially. According to Wong (2014), there are 6.1 million employed Canadians who are currently providing informal care for a family member or friend. When caring and supporting an individual who has AD, many additional responsibilities are placed on the CP. These responsibilities can lead to a significant increase in stress within their lives. Alzheimer’s Society of Canada (2010) identifies that AD and dementia puts a long-term burden on families/care partners. Not only does this role increase the stress on the CP, but it also puts their finances at risk (Lowi-Young, 2014). Often, these care partner(s) have to quit their job to be available to support their loved one. Lowi-Young (2014) explains that on average in 2011, Canadians spent approximately 444 million unpaid hours caring for someone with dementia. This number translates into an estimated 11 billion dollars in



## TR EFFECTS ON WELL-BEING

lost income for Canadian families (Lowi-Young, 2014). This figure is expected to grow to 1.2 billion unpaid hours devoted to caring for someone with dementia by 2040 (Lowi-Young, 2014). With such a significant amount of informal care taking place with family members, there is an increasing need for community-based programs to assist Canadians in adequately caring for themselves as well as their loved one (Alzheimer Society of Canada Website, 2015). The Alzheimer Society of Canada working in conjunction with the Government have identified addressing the needs of CP's and their families in the fourth objective in the national dementia plan (Lowi- Young, 2014). Caring for a loved one who has AD continues to put significant strain on families and CP's especially when it is prolonged over time without additional supports (Wong, 2014; Alzheimer Society of Canada, 2010; Lowi-Young, 2014: *Minds in Motion*, 2014). This strain on families can lead to further physical, psychological and emotional health conditions (*Minds in Motion*, 2014, p. 1).

**Suggestions for moving forward.** Alzheimer Society of Canada (2010) discusses the importance of utilizing financial resources towards activities that “have the greatest potential to maximize the quality of life” for families and individuals with AD (p.2). Alzheimer Society of Canada (2015) continues to be the leader regarding offering community-based supports for individuals with AD and their CP. To maximize the potential of funding opportunities, Alzheimer Society of Canada (2010) suggests that programs should focus on the following suggestions; prevention, delay onset, partner care impact, assigning a case manager and community programs. This section will break down and discuss these five key approaches.

## TR EFFECTS ON WELL-BEING

***Prevention.*** Since there is no medical cure for AD, it is important for Canadians to make healthy life choices to reduce the chances of developing AD. Rising Tide (2010) suggest that by increasing physical activity, individuals can decrease the occurrence of dementia incident. Belfry et al. (2014) further go on to identify that “intellectual and social engagement, control of vascular risk factors, healthy diet, and physical activity are among the most promising strategies to reduce the risk of dementia” (p. 1-4). It is not only important to keep our bodies healthy and active but keeping our minds healthy as well.

***Delay onset.*** By targeting dementia-free adults and focusing on combining “a variety of promising evidence-based strategies such as following a healthy diet and lifestyle,” we can slow down or stop the progression of the disease (Alzheimer Society of Canada, 2010, p.12). Alzheimer Society of Canada (2010) further explains that evidence-based programs and innovative programs will assist with having an impact on this aging population. It is important to recognize the diverse needs and interests of this community to create successful interventions that match the individuals’ needs and abilities. Physical activity and improved brain health are two frequently identified approaches to intervening with this population (Alzheimer Society Canada, 2015).

***Caregiver.*** Moving forward, increasing pressure will be placed on CP to support and meet the needs of the individual with AD and other dementias. As well, there will be a larger role for care partners to assist with programming (transportation, behavior management, assistance, etc.) in an attempt to keep individuals with AD in their homes to lower the economic costs of health care (Alzheimer Society of Canada, 2010). Alzheimer

## TR EFFECTS ON WELL-BEING

Society of Canada (2010) suggest that “education and development of stage-specific coping skills both for the person with dementia and their caregivers, are important aspects of care plans” (p.3). Leahey and Singleton (2011) further suggest that it is beneficial to include CP in the session with their loved one as it may assist in transferring these skills and resources that are learned to the home environment more efficiently.

***Assign a case manager.*** Having a case manager assigned to each individual would ensure that the individual with AD as well as their family would be connected to the appropriate supports and resources (Alzheimer Society of Canada, 2010). Sinha (2012) identifies how a team-based approach would prevent gaps in services and effectively meet the needs of the individuals. This would further encourage multiple disciplines to work together to coordinate and develop appropriate evidence-based programs. Programs like the Alzheimer’s Society of Canada (2015) are aware of the services that are available within their communities for both the individual with AD and their families, as well, these agencies are able to make referrals to appropriate programs.

***Community programs.*** To decrease the pressure on long-term care (LTC) facilities and other institutions, there is going to be a growing need for community-based programming to meet the needs of the above-mentioned approaches. Kuntsler (2002) emphasizes that some of the benefits of aging at home are increased self-determination, less restrictive environment, connection in the value of the home and quality of life. Remaining in one's home allows individuals to experience autonomy and maintain their identity. To ensure that we are providing the “right care in the right place at the right

## TR EFFECTS ON WELL-BEING

time means that we have to strengthen and invest more in our home care and community support service sectors” (Sinha, 2012, p. 10).

According to Alzheimer Society of Canada (2010), there needs to be further investment in dementia research, specifically on the quality of life and health services. It is also important to gain a better understanding of the significant role that CP play in accessing community programs. It is important to recognize the emotional and financial burden that this disease has on CP to adequately support these individuals through community programs. Further research is required to explore various approaches focusing on the increased use of current frameworks and utilizing best practices. Therapeutic recreation is one approach that employs innovative and adaptable programming that can work within the needs of this population to assist communities.

### **Alzheimer’s Disease – Steps Moving Forward**

As Lowi-Young (2014) identified, “three out of four Canadians know someone who is affected by Alzheimer’s or another dementia” (p. 6). Alzheimer’s disease affects everyone, whether it’s through directly knowing someone that is impacted by the disease or whether it is through the impact that this disease has on our economy and healthcare system. Alzheimer’s Society of Canada (2014) describes AD “as a progressive and degenerative disease that destroys brain cells. It is the most common form of dementia, accounting for 64% of all dementia’s in Canada.” While several early symptoms of AD appear similar to those of the aging process, AD is not a normal part of the aging process (Shan, 2013; Alzheimer’s Society Canada, 2014). Early detection is critical to intervene and to slow down the progression of the disease (Belfry et al., 2014). Shan (2013)

## TR EFFECTS ON WELL-BEING

explains that the “diagnosis is difficult in the early stages, and effective treatment remains elusive” (p. 32). The challenge with this disease is that the diagnosis is often missed or delayed and passed off as part of the aging process (Alzheimer’s Society of Canada, 2010). Holland (2013) identified that there is approximately a 2.8-year gap between when symptoms occur to when an individual gets a diagnosis. Most individuals fear the stigma, criticism and embarrassment associated with the disease and often hide early symptoms for as long as they can, which interferes with attempts for early intervention (Cohen, 1999). The most commonly identified first symptom is short-term memory loss. This is often misidentified as forgetful, or a part of the aging process, as their long-term memory during these early stages typically remains intact. Cohen (1999) identified that other symptoms are present up to two years before memory loss initiates. These symptoms are a decrease in the sense of smell, visual disturbances, hearing loss, depression and a decline in cognitive abilities (Cohen, 1999). In addition, to these symptoms there is also a “decline in reasoning, which involves establishing connections, forming judgments and making decisions” (Shan, 2013, p. 33). Alzheimer’s disease primarily affects those who are in their 60’s or 70’s, at this point the disease will affect 1.5 out of 10 people in this age range (Cohen, 1999). As the illness progresses, it will continue to shrink the tissue in the brain, “the brain segment subjected to the greatest amount of damages is the hippocampus, the area of learning and memory, and it plays the most crucial role in Alzheimer’s. The second most frequently affected area of damage with resultant atrophy (shrinkage of tissue) is in the brain’s temporal lobes” (Cohen, 1999, p. 10). These symptoms are irreversible and will continue to cause further “loss of

## TR EFFECTS ON WELL-BEING

short term and long term memory, judgment and reasoning, as well as change in mood, behavior and the ability to communicate "(Alzheimer's Society of Canada, 2010, p. 3). This disease will continue to deteriorate until it eventually takes the life of the individual. The longer we live, the more likely the reality of this disease will affect our lives more progressively which further feeds the need for more research and alternative approaches.

In Canada, the Alzheimer's Society is the leading voice for individuals with AD and their family. Based on several research initiatives a growing concern has been identified, that due to the diversity of AD, that many people and organizations lack awareness of how to interact/care for older adults. Future programs need to focus on addressing and preparing families and the community for appropriately interacting with these individuals (Alzheimer Society of Canada, 2010). Due to the high number of people living with AD, "there is a significant need for support networks and programs that can optimize functioning and independence of persons with dementia" (Leahey & Singleton, 2011, p. 135). Independence is an important aspect to focus on, especially when current community approaches aim to keep individuals in their community and in their homes as long as possible to reduce the costs and burden on LTC facilities. However, Kunstler (2002) identifies that for "older adults living in their homes, declines in health status may lead to social isolation, decreased physical activity, lack of intellectual stimulation and the inability for self-care" (p. 187). To successfully approach this, Alzheimer Society of Canada (2010), suggests that alternative programs have to be considered. Two critical areas for programs to target are physical activity as well as brain health. Brain health is a term that is used by the Alzheimer Society of Canada (2015) to

## TR EFFECTS ON WELL-BEING

promote healthy life styles choices that can “improve your brains ability to sustain long-term health and fight illness” (“Brain health”). Some of the strategies that are suggested are: to participate in cognitive activities, be social, eat healthy, be physically active and to protect one's head (Alzheimer’s Society of Canada, 2015). “Physical activity has a significant effect on brain health and regular physical activity increases the quality of life for older adults with dementia” (Minds in Motion, 2014, p.1). Physical activity has a variety of benefits to offer individuals who have AD, such as improved balance, reduced falls and improved quality of life. El-Kader (2011) found that aerobic exercise showed an increase in not only exercise tolerance but the quality of life as well. Activities that focus on brain health have the ability to assist individuals in preventing the diseases from progressing as well as practicing skills for problem solving, decision making and maintaining memory, which also contributes to the quality of life (Belfry et. al, 2014; Hood & Carruthers, 2007).

The Alzheimer Society of Canada has initiated several research initiatives to address this crisis. One program that had been launched is Minds in Motion (MiM), which utilizes the fundamental aspects of physical activity and brain health. Minds in Motion (MiM) is a “community-based program designed for persons in the early to mid-stages of dementia and their care partner who attend with them” (Gnaedinger, 2013, p. 1). This program initially originated in British Columbia and included two critical sections of the program; one hour of physical activity and one hour of social component (games, snacks, refreshments, etc.) that was facilitated in municipal community centers or senior centers. By offering these programs in public facilities, it enabled the participants to see

## TR EFFECTS ON WELL-BEING

what other community programs were available for the individual with AD, but more specifically for the care partner. This program provides a safe space for individuals to meet and not have to worry about being marginalized or judged based on their interactions (Minds in Motion, 2014). Minds in Motion is a program where the participants could meet others that are going through the same experiences. During the program, participants have the opportunity to build skills, increase knowledge, and participate in activities with their loved one while also aiming to improve their quality of their life (Gnaedinger, 2013). Gnaedinger (2013) states there are no other programs for this population offering both physical activities as well as a social aspect. Most programs focus on isolated areas of improvement. This program, however, addresses all aspects of well-being (physical, emotional, social, psychological, etc.). Also, this program is also unique in that it aims to provide a positive experience and outcome for both the individual with AD and their CP together (Gnaedinger, 2013). Joint programs allow, “loved ones to engage in a manner that is not influenced by illness...[the] relationship becomes normalized” (Minds in Motion, 2014, 2). The Minds in Motion program in British Columbia did not do formal evaluations. However, some of the informal feedback that was gathered were that the program:

improved balance, mobility, flexibility and alertness, improved comfort with their own situation, improved confidence, freedom to work within their own limitations, independent of their care partner for a short time in a stress-free environment, improved cognitive functioning, decreased isolation, increased relationships and enjoy success (Gnaedinger, 2013, p. 6-7).



## TR EFFECTS ON WELL-BEING

**Alzheimer's disease in Ontario.** In 2012, "Ontario set out a bold new vision to make the province the healthiest place in North America to grow up and grow old" (Sinha, 2012, p.2). Due to the financial concerns of the area and the pressure that the aging population was proposing, Sinha (2012) identified that Ontario needs to address current programs, assess how to move forward and improve the services that are being offered. Previously Canada did not have a National Plan, which left each jurisdiction to address this concern independently (Sinha, 2012; Ambrose, 2014). This is a costly and ineffective way to address AD. In January of 2012, Ontario launched the Ontario's Action Plan for Health Care (Sinha, 2012). This Action Plan highlighted the development of a Seniors Strategy as a way to "establish sustainable best practices and policies at a provincial level that could, in turn, support the local delivery of healthy, social, and community care services" Sinha, 2012, p.2). Through this Action Plan, Sinha (2012) identified that the focus is to help older residents of Ontario to not only stay healthier but to stay in their homes longer. Ontario was the first province to prepare thoroughly and address this concern of aging in such depth. To actively move forward and to continue building upon current knowledge, Ontario took the framework of the British Columbia MiM program and continued to seek opportunities to improve the program. While attempting to assess an appropriate intervention to address this concern, Minds in Motion Ontario had sought "reputable partners to advise and/ or take the lead on the establishment of an evidence-based framework" (Minds in Motion, 2014, p. 3). From this, it was determined that the 'Social Connectedness' portion of the program would be developed utilizing the Therapeutic Recreation framework, grounded by the Leisure and

## TR EFFECTS ON WELL-BEING

Well-being Model of TR during their 2-year pilot program (Hood & Carruthers, 2007).

Before this partnership, the British Columbia MiM program functioned the ‘Social Connectedness’ portion of the program as an unstructured social time. During this time, the participants were encouraged to have a snack and play the games that were made available to them. Through utilizing a TR framework, programs can be used to capitalize on the quality of the experience that can be gained during this time. The Minds in Motion program is a, “low-cost, flexible, affordable program, welcomed in community/seniors centers and highly valued by clients, which offers a multitude of physical and social benefits to both persons with early to mid-stage dementia and their care providers, not only during but also between and after programming time” (Gnaedinger, 2013, p. 15). Sinha (2012) emphasizes the importance of ensuring that Ontario is spending our tax dollars on the “most effective and efficient way possible to help ensure the future sustainability of our systems, programs and services” (p. 8). This supports the importance of programs like the MiM Ontario pilot program to fill the need for evidence-based programs to track, document and support future quality programs. In the development of the MiM social connectedness portion of the program, this researcher connected with past facilitators of the MiM program in British Columbia (BC) to identify typical activities that the participants were currently engaging in during the social time. This researcher used some of the activities that were identified by the BC MiM program to infuse a therapeutic recreation program. This researcher developed a manual for the facilitators to use to implement the seven-week program. Each session was categorized into one of five session topics that were components of Carruther and Hood’s (2007)

## TR EFFECTS ON WELL-BEING

Leisure and Well-being Model (authentic leisure, happiness, strengths, cognitive resources, and leisure interests). During each session, the facilitators had the option of multiple activities that they could offer. Facilitators were encouraged to select programs that are the best fit for their particular group to adequately address the specific component of the LWM. The purpose of the social connectedness program is to utilize therapeutic recreation to facilitate the meaningful activity component of the Minds in Motion program. The program used interactive and engaging activities to enhance individual strengths and personal resources.

The Social Connectedness program strives to take generic games and activities and infuse the therapeutic recreation content to attain the session goals and objectives. This adaptation of basic games/ activities allows the participants to experience many benefits, over and above “simply” having fun. Since none of the facilitators are Certified Therapeutic Recreation Specialists, the Social Connectedness facilitation guide provided details descriptions on how to infuse the programs with the specific content required for that session to meet the goals and objectives of the activity. The facilitation guide was structured so that there was an overall introduction to the key focus of the session (e.g., Authentic leisure, happiness, etc.). This introduction provided the facilitator with the essential background information that they required to facilitate the session and help guide conversations and discussions with the participants and their care partners. The information that was provided in this overview was not to be read to the participants and their CP’s but was generic background information that was

## TR EFFECTS ON WELL-BEING

catered to the particular topic that they were focusing on each week. The facilitator had an option of three to six activities to choose from for each key focus for the sessions. Each of these activities had been slightly adjusted from their original form to promote/ concentrate on the critical discussion for that week. Along with the activity being modified to ensure that it covered the goals and objectives of the session, there were discussion questions that were to be used by the facilitator at the end of the activity to assist the participants and their CP's with making the connection and infusing the activity that they participated into the key points that were to be absorbed during the session. To continue this learning opportunity, the participants had the option to complete a take home activity that further allowed the participant and their CP to connect the learning content through another activity.

The first session of the MiM program is authentic leisure. Authentic leisure is defined as “the purposive selection of leisure involvement that is reflective of essential aspects of the self” (Hood & Carruthers, 2007, p. 312). These activities were used to orient both the participants and their care partners to the program and each other. The activities were designed to encourage the participants and CP's to interact and express parts of their interests and identity to the group in a safe environment. Through exploring these activities, it was intended that the participants and CP's may find things that they have in common with each other. Participants and CP's are encouraged to participate and share only the information that they were comfortable sharing with the group. Through providing activities

## TR EFFECTS ON WELL-BEING

that allow the group to get to know a bit about each other, it was anticipated that these connections would further enhance the quality of the future sessions.

- Session one: Authentic Leisure

Goal: For participants to identify their individual strengths and values through authentic leisure experiences.

Objective #1: By the end of the session, participants will be able to identify the leisure activities that most reflect their authentic selves.

Objective #2: By the end of the session, participants will be able to identify the two most significant influences that their leisure activities have had on their identity development throughout their lives.

Objective #3: By the end of the session, participants will be able to identify why each activity was important to them at various stages throughout their life.

Activity options:

- Thumb ball
- My ideal day
- Two truths and a lie
- The good, the bad and the ugly

These activities were selected to reflect authentic leisure as they all allowed the participants and CP's to get to know each other through identifying leisure interests and activities that they used to identify with or currently identify with in order to connect. This first session was designed to function as an icebreaker session to get to know each other in a safe way to set the foundation for the remaining sessions to

## TR EFFECTS ON WELL-BEING

come. Through the participation of these activities, the participants and CP's could share little pieces of themselves that they were comfortable sharing with the group. Facilitator conversations were to be used to reflect on whether or not the activities that the participants and CP's identify are the activities that have had an impact on their identity throughout their life. As well, the facilitator were to moderate group discussions to assist the participants in identifying if their leisure interests have changed throughout the various stages of their life. The take home activity was a reflection worksheet where the individuals discussed which activities were important to the person at different stages of their life. This take home activity was discussed and reflected at the beginning of week two's session as a brief review.

Session two and three focused on happiness. Happiness takes different forms for all individuals. Individuals experiencing AD and their CP often experience various levels of stress on a day-to-day basis. The activities that were offered during this section of the program were designed to encourage the participant and the CP to pause and identify what made them happy in the past as well as identify general things that bring them happiness in their everyday lives. Participants and CP's were encouraged to re-identify things that make them happy and to try and make time in their lives to explore these things that make them happy to increase happiness in their life.

- Session two: Happiness

Goal: For participants to understand the value of happiness in their lives.

## TR EFFECTS ON WELL-BEING

Objective #1: By the end of the session, participants will be able to identify the role that happiness currently plays in their lives.

Objective #2: By the end of the session, participants will be able to identify three moments of happiness that they currently create for themselves in their day-to-day lives.

Objective #3: By the end of the session, participants will be able to identify ways to increase their happiness in the future.

Activity options:

- Happy moments
- Card Connection
- Happiness bingo
- Spreading happiness
- Keep the happiness rolling
- A trip to the beach

Through the various activities, it was intended that the participants would be able to identify daily moments that make them happy. With the assistance of the activity structure and facilitators discussion questions, the participants and CP's had the opportunity to be able to indicate the role that happiness plays in their day-to-day life. Often this session is to encourage individuals to pause and be mindful of their daily interactions and decisions and focus on why they do them and how it contributes to their overall well-being. The content of this session encouraged individuals to concentrate on the main things that make them happy or could increase their happiness and to help them

## TR EFFECTS ON WELL-BEING

to make sure that they make time for these ‘happy moments’ each day or as often as they can. Through participating in the session with other individuals, the participants and CP’s had the opportunity to connect with a ‘happy moment’ that another person shared and could either ask questions or pursue the ‘happy moment’ themselves, further expanding their happiness repertoire to attain their previously identified benefits that happiness has in their life. The take home activity for this session encouraged the participants and their CP to take time each day for the next week to pause and intentionally do something that made them happy. This activity was intended to help the individuals to try new activities and then reflect on who they did the activity with and then to determine if it is something that they would like to do again or not.

- Session three: Happiness – continued

Goal: For participants to develop the knowledge and skills to enable them to find and improve happiness in their everyday life.

Objective #1: By the end of the session, participants will be able to identify current activities of everyday life that increase their happiness.

Objective #2: By the end of the session, participants will be able to identify various strategies for increasing their happiness.

Objective #3: By the end of the session, participants will be able to identify the benefits of happiness.

Activity options:

- Happy moments
- Card Connection



## TR EFFECTS ON WELL-BEING

- o Happiness bingo
- o Spreading happiness
- o Keep the happiness rolling
- o A trip to the beach

This session further encouraged the participants and their CP's to reflect on the role that happiness plays in their life. The activities continued to promote discussions on things that participants and CP's do on a daily basis and point out what within those activities bring them happiness. Some of the activities encouraged the participants to look at images of different activities to discuss how that image makes them happy and how they work that activity into their daily routine while other activities had them write out key activities that bring them happiness and share it with others. These activities encourage discussions on how the participants and CP's could work happiness into their daily lives. The participants and CP's were able to discuss barriers that they may face and brainstorm potential solutions as a group. This was also intended to help the CP's to see and focus on positive moments, even when they are busy and are dealing with stressful situations. Throughout the activities, the facilitators were to encourage conversations on what benefits the individuals. Discussion questions help the individuals to explore the role of happiness in their life further. The take home activity provided a seven-day challenge of small daily activities for the participants and CP's to do to focus on increasing their happiness. They could identify if the activity did or did not enhance their happiness to determine whether they would consider doing that activity again. The participants also had the option to complete their own list of daily happiness challenges to complete.

## TR EFFECTS ON WELL-BEING

Session four focused on strengths. The programs that were available for this session enabled individuals to connect with their strengths. It is easy to become focused on deficits in day-to-day life, especially while experiencing Alzheimer's disease. The activity options that were available for this session allowed both the participant and their CP to look and remember the strengths that they both possess. The participants and CP's were to learn to take negative situations and refocus on the strengths of their loved ones. Through identifying their loved one's strengths, the CP's could then use these strengths to connect further with their loved one outside of the program through capitalizing and enhancing their strengths.

- Session four: Strengths

Goal: For participants to further understand the value of personal strengths.

Objective #1: By the end of the session, participants will be able to identify three of their own personal strengths.

Objective #2: By the end of the session, participants will be able to identify how weaknesses can be turned into strengths.

Objective #3: By the end of the session, participants will be able to identify the benefits that their strengths bring to their life.

Activity options:

- I'm unique because...
- Strengths puzzle
- Reverse thinking
- What animal am I?

## TR EFFECTS ON WELL-BEING

These activities were focused on encouraging the individuals to identify what they are good at and what strengths they have. As well, the participants and CP's are invited to identify strengths in others to help others who are struggling to see what their strengths are. These activities aimed to infuse the learning component to the activity to encourage CP's to look at their loved one who has AD and not see them from a deficit mindset, but rather to identify and celebrate their strengths. These activities focused on changing the mindset from not viewing things as weaknesses, but to see them through a difference lens where they could see it as a unique strength. Through facilitated discussions individuals could identify the various benefits that their strength brings to not only themselves but others as well. This session celebrates everyone's uniqueness and individuals strengths. The take home activity for this session allowed the individuals to write down and reflect on their key strengths that not only they see, but strengths that others have identified in them as well.

Session five and six focused on building the cognitive resources for both the participant and their CP. Through enhancing one's cognitive resources, it was anticipated that it would enable the participants to engage fully in their environment. Through participating in activities focused on cognitive resources, its intent was to maintain or even possibly improve their cognitive functioning. CP's were introduced to activities that they could engage in with their loved one to promote and build cognitive resources.

## TR EFFECTS ON WELL-BEING

- Session five: Cognitive resources

Goal: For participants to maintain and/or build their capacity for improving cognitive resources (e.g., Memory, concentration, problem solving, goal setting, etc.)

Objective #1: By the end of the session, participants will be able to identify leisure activities they have engaged in throughout their life, that have helped build their cognitive resources.

Objective #2: By the end of the session, participants will be aware of at least one new leisure activity they can engage in with others, while further building their cognitive resources.

Objective #3: By the end of the session, care partners will know of alternative ways to positively interact with their loved ones, while improving both their own and their loved ones cognitive resources.

Activity options:

- Name grid
- Newspaper puzzle
- Name that sound
- Sock it to me
- Scategories

These session activities were focused on introducing/ re-introducing leisure activities that are not only fun and engaging, but to also encourage the participants and their CP's to build their cognitive resources while participating. Discussions were to encourage

## TR EFFECTS ON WELL-BEING

individuals to identify what they currently do in their lives to exercise and preserve their cognitive resources. These activities used leisure activities to encourage the individuals to exercise their brains in fun and interactive ways. These activities were intended to be activities that the participant and CP could do at home with family/ friends. The take home activity was to encourage the individuals to participate in word searches, cross words, Sudoku, etc. with their loved one to keep them active while participating in whatever cognitive activity they enjoy.

- Session six: Cognitive resources – continued

Goal: For participants to maintain and/or build their capacity for improving cognitive resources (e.g.. Memory, concentration, problem solving, goal setting, etc.)

Objective #1: By the end of the session, participants will have developed the skills necessary to brainstorm solutions as a member of a group.

Objective #2: By the end of the session, participants will be familiar with a variety of activities that they can engage in to promote positive interaction and to build cognitive abilities.

Objective #3: By the end of the session, participants will be able to identify various ways to use leisure opportunities in their everyday life to maintain or improve cognitive abilities.

Activity options:

- Name grid
- Newspaper puzzle

## TR EFFECTS ON WELL-BEING

- o Name that sound
- o Sock it to me
- o Scategories

The activities in this session further encourage the individuals to work their cognitive abilities through leisure activities and play. Optimally, the participant and CP were to identify and learn a new activity that they can do together that will challenge them cognitively. During these activities, the CP's were encouraged to let their loved one complete as much of the activity as possible on their own. Often CP's get in the role of doing things for their loved one with AD. However, these activities encouraged the participants to use their cognitive resources that they have to further develop their skills. The members were able to use familiar situations and activities to practice decision making/ brainstorming in a safe environment. These activities and the take home activity were to encourage the individuals to incorporate cognitive leisure activities into their daily lives. Facilitator discussions were designed to help individuals to think of other activities that are similar to the ones that they participate in through the session that they may have participated in at other stages of their life. This aimed to increase the activity repertoire of the partners to encourage them to participate in cognitive activities. This was to promote positive interaction through involvement in a game/ activity that they knew of, especially after having a variety of activities that they had become familiar with after the last two sessions.

The seventh session was focused on leisure interests. Participating in leisure opportunities can provide individuals with a variety of benefits. The activities in this

## TR EFFECTS ON WELL-BEING

session were to encourage participants and CP to discuss the past, current and future leisure interests. The activities identified that while individuals may not be able to participate in activities that they once enjoyed due to a variety of limitations, there are other alternative activities that they could consider instead. Through identifying leisure interests, both the participant and the CP can explore appropriate leisure opportunities within their community.

- Session seven – Leisure interests

Goal: For participants to have greater awareness of the importance and impact of leisure on well-being, throughout life.

Objective #1: By the end of the session, participants will be able to identify and understand the various leisure activities that have had a significant influence on their lives.

Objective #2: By the end of the session, participants will be able to identify the physical, emotional, social, cognitive and spiritual benefits that their leisure interests add to their lives.

Objective #3: By the end of the session, participants will be able to identify some future potential barriers they may face in terms of leisure involvement as well as ways to overcome or adapt to these barriers.

Activity options:

- Who am I?
- Leisure Jenga
- Horse races

## TR EFFECTS ON WELL-BEING

Each of these activities were designed to encourage the participant and CP to identify the variety of leisure activities that they have participated in throughout their life. Through the activity questions and the facilitator discussion, the individuals were encouraged to make the connection on the influence that leisure has had on their life. They were encouraged to identify how they have used leisure in the past (stress relief, socialization, etc.). This was to promote the importance of remaining active throughout life to continue to use leisure for all of the individual benefits that it provides. These activities were designed to not only set up the discussion on what currently or in the past they have participated in but also to be open and discuss potential barriers that they currently do or could face in the future in order to brainstorm individually and as a group how to either overcome or adapt to a barrier. These discussions are crucial, as some of the identified barriers may relate to everyone at some point, whereas some may relate to only some. However, these activities provided opportunity to facilitate that open discussion to overcome a variety of barriers. The take home activity encouraged individuals to pause and reflect and identify what leisure activities they participate in currently and outline why they participate and what benefits they get from it. It is an excellent tool to use to remain to motivate to keep active and to take part in leisure activities throughout the lifespan.

### **Therapeutic Recreation – Leisure and Well-being Model**

Therapeutic recreation is an approach that utilizes innovative programming that has been identified as a program approach for working with this population. The MiM Ontario program used the TR framework for the ‘social connection’ portion of the pilot



## TR EFFECTS ON WELL-BEING

program. Therapeutic recreation has the ability to benefit not only the individual with AD, but their CP as well. In addition, this approach does not just focus on one specific deficit to improve upon, but rather it takes a more holistic approach in looking at the individuals strengths and capitalizes on them to improve the individuals overall positive emotion and well-being.

The particular TR framework that was utilized for the Minds in Motion Ontario Pilot program was Hood and Carruthers (2007) Leisure and Well-being Model (LWM) in the development of the sessions. Hood and Carruthers (2007), Leisure and Well-Being Model is a multidimensional Therapeutic Recreation Service delivery model that does not look at an individual's deficits, but rather the whole person when striving for a distal goal of optimal well-being. Service delivery models are tools that professionals use to determine their scope of practice and is used to determine appropriate and effective interventions for clients. The LWM is a TR service delivery model that starts with the end in mind. This model identifies well-being as the targeted outcome of TR interventions. In this model, Hood and Carruthers (2007) identify a focus on two dimensions of well-being: 1) "positive affect, emotion and experience on a daily basis", and 2) "Cultivation and expression of one's full potential – including strengths, capacities, and assets" (p. 279). Having long-term goals allows program designers to focus on the necessary short-term goals that are required in order to attain the desired outcome. The short-term goals that Hood and Carruthers (2007) identify as being key to building a life of meaning are: 1) "Enhancing leisure experience", and 2) "Developing resources" (p. 301). Enhancing leisure experiences connects to the concept that through

## TR EFFECTS ON WELL-BEING

the use of intentional leisure pursuits, professionals are able to capitalize on the benefits that can be gained through these experiences as individuals are actively involved in the experience and more capable to absorb learning opportunities. Through this short-term goal, “the leisure experience has a central and crucial role to play in the development of resources and, ultimately, the well-being of clients” (Hood & Carruthers, 2007, p. 310). This model identifies five research supported ways in which to cultivate and enhance leisure experience (savoring leisure, authentic leisure, leisure gratifications, mindful leisure and virtuous leisure). Through these five approaches, Hood and Carruthers (2007) identify approaches that TR professionals can use when working with clients. Hood and Carruthers (2007) identify that focusing on enhancing the leisure experience alone has significant benefits for clients, however, the benefits can be further enhanced when programs are designed to also develop resources. Hood and Carruthers (2007) identify five dimensions of resource development (psychological resources, social resources, cognitive resources, physical resources and environmental resources). As previously mentioned, the optimal way in which to develop resources is through having enhanced leisure experiences, this provides an opportunity for increased positive emotion, which in turn further allows individuals to build upon their strengths to further develop their resources. Developing ones resources allows individuals to be better prepared and equipped to deal with stresses or problems that occur on a daily basis as the individual will already have the resources need to cope, or they will have the resources to get the support that is required (Hood & Carruthers, 2007).

## TR EFFECTS ON WELL-BEING

The LWM allows individuals to focus on their goals while also building and mobilizing their resources (Hood & Carruthers, 2007). Due to the broadness of the LWM, TR practitioners are able to utilize this model with a variety of populations in a variety of settings. Therapeutic recreation specialists are able to take a client centered approach and utilize the model in a variety of ways in order to strive for the desired outcome of well-being for their client. Hood and Carruthers (2007) identify that, “it is anticipated that therapists will select different aspects of the model for program development based on the needs and aspirations of the client group served, their existing capacities and the setting in which they are served” (p. 319).

One of the main advantages of using this model is how well-being is not viewed as a distinct end point, but rather an ongoing process of continuously building one's strengths and resources throughout the life process. The LWM “reflects [a] positive, strength-based approach and proposes that the outcome of TR services should be enhanced well-being” (Hood & Carruthers, 2007, p. 172). As mentioned earlier, there is no cure for AD, however as Belfry et. al (2014) stated, social engagement is one of the factors that could potentially reduce the risk of AD. The Alzheimer Society of Canada (2015) highlights the role that AD plays in influencing the quality of life for both the individual with AD as well as their CP. Therapeutic recreation can utilize various approaches to promote positive emotion and well-being with a distal goal of improved quality of life (Hood & Carruthers, 2007). Carter, Van Andel and Robb (2011), suggest that TR can also provide valuable services to the CP regarding enhancing their strengths, skills, and resources through participation with their loved one. Through the involvement,

## TR EFFECTS ON WELL-BEING

CP can have the opportunity to: further develop effective coping skills, to connect with others who are going through similar situations, to identify positive ways to participate with their loved one, and to take the time to focus on their self-care. Through taking part in a TR program with their loved one, both the individual and the CP will be able to step outside of their current roles and function independently and re-learn how to enjoy their time and experience with their loved one again, and create new and positive interactions where both individuals will improve skills and build strategies to use outside of the program. In terms of programming for this population, TR sessions aim to provide the appropriate supports and knowledge that mainstream programs are typically unable to meet. Mainstream programs are not generally prepared to facilitate programs for individuals who have dementia or AD, so these individuals are often excluded and isolated within their community programs. Therapeutic recreation interventions are strategically chosen and designed in order to meet the needs of that specific population. Kolanowski, Beuttner, Costa and Litaker (2001), go further to explain that TR activities are “differentiated from divisional activities in that they are intended to yield specific outcomes, such as improvement in physical or behavioral functioning” (p. 221).

Therapeutic recreation utilizes various frameworks and knowledge to effectively plan for their population. A minor example of this would be through using Mannell and Kleiber’s (1997) concept of continuity through leisure pursuits and offering programs that were previously enjoyable activities for the seniors in order to keep them engaged while utilizing the strength of long term memory of someone with AD compared to attempting to rely on an individual’s unreliable short term memory to learn a new skill.

## TR EFFECTS ON WELL-BEING

Alzheimer Society of Canada (2010) suggests that there be an investment in all areas of dementia research including quality of life. “TR programs have been demonstrated to be an effective intervention for persons with Alzheimer’s as they relieve anxiety, reduce confusion and improve mood” (Lahey & Singleton, 2011, p. 137).

Silvers, Wilson, and Westgate (2010), further go on to explain that TR produced significantly improved levels of depression, increased activity and alertness levels and lower fall rates.

Alzheimer Society of Canada (2010) suggests the need for innovative approaches to help with the progression of AD. Therapeutic recreation is one of the many approaches that could significantly benefit not only these individuals but CP’s and communities as well. Therapeutic recreation can continue to adapt programming and adjust to meet the needs of the individuals involved in programming. This is one approach that can be utilized in many ways to address this issue.

### **Positive Emotion, Strengths and Well-Being Through TR Programming**

The use of the Leisure and Well-being Model (LWM) of TR, focus on the strengths of the person with AD and their CP (Hood & Carruthers, 2007). This is in contrast to other types of interventions, which work closely with the medical model, focusing on individual deficits (Carter, Van Andel & Robb, 2011). The LWM model looks toward the distal goal of improving the overall well-being through focusing on positive emotion and strengths of the individual instead of remediating the disease or illness. There are many benefits to identifying a person's abilities and capitalizing on those to improve well-being. Fredrickson (2000) defines how skilled professionals can

## TR EFFECTS ON WELL-BEING

build upon current abilities when she states that, “[t]he capacity to experience positive emotions remains a largely untapped human strength” (p. 2).

Until recently, most research focused on the effects that negative emotion has on individuals, due to the well-documented adverse health effects associated with negative emotions such as stress, depression, and overall weakened the immune system.

Fredrickson (2000) suggests that by focusing on positive emotion that interventions could not only counteract/ regulate negative emotions but that it could also be used in prevention and treatment to overcome the effects of negative emotion. The impact of positive emotion extend beyond the current moment, and resonates with our thoughts and memories, allowing people to continue to benefit from a single moment of positive emotion. Through utilizing a seven-week TR program that focuses on enhancing positive emotion and well-being, interventions are designed with the intended outcome of facilitating positive emotion in participants. Through explicitly creating these programs that promote play, joy and other positive emotions, Fredrickson (2000) identifies that in these activities, the individuals can not only experience positive emotion but also broaden their thought process by allowing the individuals to discover new ideas and actions; also enabling them to “build their physical, intellectual, social and psychological resources” (Fredrickson & Joiner, 2002, p. 172). Fredrickson (2000) further identifies that through playful situations, individuals can broaden their thought repertoire in a safe and fun way, mostly out of natural reaction/ instinct. From this, individuals build transferable skills and resources that can be accessed in the future. As Fredrickson (2000) identifies, positive emotion creates thought patterns that are functionally usable.

## TR EFFECTS ON WELL-BEING

From this perspective, Fredrickson (2000) describes that through various play experiences, individuals learn problem-solving skills that they can not only use during these moments of play but in other parts of their lives as well. This demonstrates that positive emotion is not only hedonically pleasant and rewarding but rather it also enables individuals to use and develop their current skills and resources. Though participating in the MiM program, individuals will have the opportunity to use their existing skills and natural responses to playful interventions to utilize the skills hopefully in other aspects of their personal lives. Participants may not realize the benefits that they may inherit by participating in activities, but the research will identify if the members feel the benefits that can be gained. Fredrickson (2000) suggests that positive emotion can be further used to, “optimize health and well-being” (p. 7).

As identified earlier, TR through the lens of the LWM Model does not look at the deficits of an individual, however it begins with the end point/ overall goal in mind, which, “allows program designers to examine factors that may contribute to attainment of long-term goals,” which for this study is increased well-being (Hood & Carruthers, 2007, p. 280). Hood and Carruthers (2007) identify that well-being can be defined as a “state of successful, satisfying and productive engagement with one's life and their realization of one's full physical, cognitive and socio-emotional potential” (p. 279). Through looking at the long-term goal of well-being, the program developer could strategically design sessions that could assist individuals in reaching this objective.

Hood and Carruthers (2007) explain that the key to well-being is enhanced when individuals building a life of meaning. In order to attain this, Johnson, Witlatch and

## TR EFFECTS ON WELL-BEING

Menne (2014) as well as Simone and Haas (2013) discuss the importance of becoming socially and cognitively engaged as well as active to improve their well-being. Johnston, et al. (2014) identified that an overall improvement in well-being occurred as the result of participating in more activities, regardless of the individuals cognitive abilities. The more activities an individual engaged in for further develop and capitalize on their strengths, the higher their levels of quality of life and well-being that were being reported. “[R]egardless of impairment status, can benefit from maintained physical and social activity levels” (Johnston, et al., 2014, p. 156).

Simone and Haas (2013) continued to identify that, “two factors have been found to predict subjective well-being are social activity and health” (p. 276). This emphasizes the importance of encouraging older adults, regardless of their cognitive abilities to remain active in their communities. The Public Health Agency of Canada (2010) identify that as individuals age, they become more sedentary and isolated which can lead to other health concerns. Canada could benefit from having communities that offer programs and opportunities for this aging population in order to assist these individuals. Therapeutic recreation activities can empower these individuals to build upon their own skills and provide opportunities for individuals to keep both their bodies as well as their minds active (Belfry et al., 2014; Carruther & Hood, 2007). Fauth et al. (2012), support the use of programs that involve both the individual with AD as well as their CP as “closer relationships between caregivers and care recipients with dementia are associated with positive outcomes for care recipients” (p. 699). It is important to create social



## TR EFFECTS ON WELL-BEING

environment that enables the individuals to find a sense of meaning within their community and with their loved one as well (Fauth, et al., 2012).

### **Secondary Research Analysis**

Secondary data is one of the methods that researchers utilize for conducting research which is defined as “the use of data by another researcher in a way in which the primary researcher had not intended” (Singleton, 1988, p. 233). Through utilizing this approach, researchers can access existing data which they can further explore to gain new knowledge. Vartanian (2011) identifies that secondary data often is less expensive and takes less time to organize as the data is already collected and input into a database. There are limited resources that identify the role that secondary data plays regarding leisure research. However, Singleton (1988) did state that secondary data has “been found to be a viable source of information for leisure researchers” (p. 235). Singleton (1988) was able to see the benefits that secondary data could have for leisure research regarding expanding current knowledge of the field. Vartanian (2011) goes on further to discuss that the quality of secondary data sets is typically high making the results more meaningful. Researchers may not have input on the design of the study. However, they can reap the benefits of valid and reliable data in a way that is cost efficient and has limited impact on individuals that would be required to conduct a new study. Vartanian (2011) demonstrates this by stating that, “in many ways, users of secondary data trade control over the conditions and quality of the data collection for accessibility, convenience, and reduced cost of time, money and inconvenience to participants” (p. 1). Due to the complexities and the impact that data collection can have on individuals who

## TR EFFECTS ON WELL-BEING

have AD and their care partner, secondary data analysis is reasonable to approach to use when collecting data on this population.

### **Conclusion**

It is projected that by “2038, 1,125,200 people or 2.8% of the Canadian population will be living with dementia if no active intervention occurs regarding preventing or to slow the progression upon onset” (Minds in Motion, 2014, p.1). There is a need for quality programs within communities in addition to what is currently offered. These new interventions have to build off of current knowledge and continue to change and adapt to the needs of the community change. Ontario’s Aging at Home Strategy was the current government’s, “first major attempt to invest in a wider range of programs and services that could support the development of a more integrated continuum of care. Continuing and strengthening this commitment to invest more in home care and community services will do much to help Ontarians staying healthy and staying at home longer” (Sinha, 2012, p.11). Without focusing on, building upon and improving upon the current community programs, many older adults who remain in their homes will continue to place a substantial burden on the healthcare system and their CP (Sinha, 2012). “Support programs for patients and their informal caregivers were also shown to provide a significant reduction in the economic burden related to dementia by delaying admission to LTC resources, there are additional emotional and quality of life benefits, as well as economic benefits due to the decrease in informal caregiving burden” (Rising Tide, 2010, p. 14). Therapeutic recreation is a profession that uses innovative intervention approaches that allows both the individual with AD and their CP to benefit from the

## TR EFFECTS ON WELL-BEING

program and ultimately increase their overall positive emotion and well-being while supporting individuals to remain in their communities (Kunstler, 2002). Conducting evidence-based research on a program that is actively trying to meet the needs of the community through an innovative approach at an earlier onset of AD within the community with their care partner will create a strong foundational knowledge to build upon and validate services for this population forward.

### **Chapter 3**

#### **Method**

The purpose of this study is to determine if a seven-week Therapeutic Recreation program creates an increase in participants overall well-being from the beginning of the program to the end of the program for the individuals in the MiM initiative. This Therapeutic Recreation program was specially designed for individuals with Alzheimer's disease or other dementias and their care partners. The remainder of this chapter will outline the following organizational steps in conducting this study: (a) participants, (b) description of the test instruments, (c) design of the experiment, and (d) treatment of data.

#### **Participants**

The sample of this study was taken from a single secondary data set. From this data set, a total of 333 Pre-Tests and 287 Post-Tests were completed. Only 234 participants had successfully completed the both the pre and post- test for this research. The primary study of 234 individuals in total included both the persons with dementia (53%) and their care partner (47%). The sampling criteria for the study was individuals with early to mid-stage signs of Alzheimer's disease or other dementias and their care partners. For participation in this study, it was required that the person with Alzheimer's had a consistent care partner that attended the full duration of the program. The care partner could be any individual who had a significant relationship with the participant, whether it was a spouse, a family member or a friend that would attend the program with the participant for the entire duration.

## TR EFFECTS ON WELL-BEING

### **Minds in Motion (MiM) program Procedures**

The participants in the primary study were registered in the Minds in Motion (MiM) program that was offered at one of the six locations throughout Ontario. The six locations that the MiM programs were offered at; a) Grey-Bruce, (b) Hamilton Halton, (c) Waterloo Wellington, (d) London-Middlesex, (e) Sudbury- Manitoulin and (f) Thunder Bay. Participants were recruited to participate in this study through a variety of marketing strategies to inform the public about the MiM program. The Alzheimer's Society of Ontario (ASO) developed posters and flyers (Appendix A) to have at their local Alzheimer's Society locations as well, the ASO utilized a variety of social media tools such as websites, newspaper articles, and news clippings to inform the local communities about the MiM program. In addition to this, the MiM coordinators were approaching appropriate participants of other ASO programs within their specific Alzheimer's Societies, and when it was appropriate, the MiM program coordinators were recommending these individuals and their care partners to the MiM pilot program. Before being registered for the program, the person and their care partner were assessed by the facilitators to ensure that the MiM program was the most suitable referral for the individual in their current state. Also, each pair (individual with AD and their CP) were required to pay a \$40 registration fee and complete a registration form (see Appendix B) to participate in the seven-week program. This program was intended for individuals who are experiencing early to mid-stage AD or other dementias, however, the participants did not have to provide any documentation identifying their condition. Requiring participants to prove a doctor diagnosis in order to participate in the MiM pilot

## TR EFFECTS ON WELL-BEING

program would provide a barrier for many individuals to participate. Acceptance into the program was at the discretion of the MiM program coordinator to assess if the MiM program was suitable to the participant or not. This programs appropriateness was continually monitored as the program progressed through the seven weeks to ensure that the MiM program was able to provide an optimal experience for all participants and their care partners. Ethical approval was granted by the University of Waterloo on April 14, 2014 (Appendix C), as well, ethics approval to access secondary data was granted by Brock University on April 5, 2016 (Appendix D). Participants also signed a form for Informed Consent (Appendix E), as well as for Participant consent to participate in the evaluation of Minds in Motion (Appendix F). This researcher sought ethical approval from Brock University to utilize secondary data from the MiM program to investigate the purpose of this study.

### **Social Connectedness Program**

The Social Connectedness program is the implementation of a therapeutic recreation intervention in the Alzheimer Society of Ontario's Minds in Motion program. Facilitators attended a two-hour training session to learn how to utilize the facilitator's manual and how to implement the specific activities. Each facilitator was provided a facilitators guide along with a tool kit that had all of the resources that they required to apply and evaluate the seven sessions. In the manual, each section consisted of a cover page that provided an introduction to the topic. The facilitators were told that they were not to read this information to the participants and their care partner's (CP), but rather they were to use the information for themselves to have a background, base level of

## TR EFFECTS ON WELL-BEING

understanding of each session topic. This is also where the goals and objectives of each session were identified for the facilitators to attain. This allowed the facilitators to have a clear understanding of the learning objectives that they were to attempt to achieve throughout the session.

Each section also had a session overview where it identified an introduction that the facilitators could use to greet the participants and CP's. This would guide the facilitator on how they could address the follow up from the previous weeks take home activity along with how to introduce the focus for that week. The session overview section also listed the activity options that the facilitator has to choose from for that session. The facilitators were provided with a list of three to six programs that they could pick from to run their session. Facilitators were encouraged to look through the activity options to determine which activity would be the best fit for their particular group. It was also suggested that they be prepared to run two programs in case the activity went faster than anticipated for their group, or in case the activity turned out to be an incorrect fit. In the overview, it also outlined what the take home activity was. The take home activities were intended to be an extension of the activity that they did. The take home activity allowed the participant and CP to continue to practice the skills that they were learning. The take home activity was not a requirement of participating in the Minds in Motion program. The take home activities encourage the participant and their CP to interact and have fun with each other while continuing to build their skills and resources outside of the program setting.

## TR EFFECTS ON WELL-BEING

Each session provided a full program description for each activity from which the facilitators could choose. Along with the program description that explained how to play the game, the manual also listed the equipment that would be needed to complete that particular activity, it provided a description of how to set up the activity (variations to the activity were provided), as well, discussion questions were provided. The discussion questions were to be used to reflect on the activity in which they had just participated. The discussion questions were also used to assist the participants and their CP in making the connection from the activity to the skill that they can use in their personal lives.

### **Description of the Test Instrument**

The primary study collected data on a variety of variables. For the purpose of this study, this research is going to analyze the data that was collected from the Warwick-Edinburgh Mental Well-Being Scale (WEMWBS) that was completed in the initial MiM study by Waterloo University.

*Warwick-Edinburgh Mental Well-Being Scale.* To assess and identify changes in mental well-being throughout this seven-session program, this researcher utilized the pre and post data of the Warwick-Edinburgh Mental Well-Being Scale (WEMWBS) assessment tool (Appendix G). The document ‘Measuring the impact of your work on mental wellbeing’ (2012) identify that collecting pre and post data, “tells us a lot about what strategies work best and what helps people improve and sustain mental well being.” (p. 4).

This scale will demonstrate whether or not there have been any changes in the mental well-being of its participant through the completion of the MiM program. The



## TR EFFECTS ON WELL-BEING

WEMWBS was to be completed before or on the first day of the MiM program. This scale was then to be completed during the session on the last day of the MiM program. The WEMWBS scale consists of 14 positively phrased questions on a Likert scale of one to five. As identified by Stewart-Brown et al. (2009), the WEMWBS was developed to meet the need for a tool that effectively measures well-being. This scale was selected specifically for this population due to the scales ability to assess mental well-being in a manner which is accessible to individuals who demonstrate early to mid-stage signs of Alzheimer's disease or other dementias and their care partners. This scale is suitable for this population, as it requires only a few instructions for the participants to complete. Although the WEMWBS is intended to be completed independently, the document 'Measuring the impact of your work on mental wellbeing' (2012) explained that there are limitations in utilizing an interviewer to complete the WEMWBS as it has not been tested, however it does identify that there are some individuals/ populations that could require support completing the scale. Throughout completion of the WEMWBS scale, participants and their care partner were encouraged to complete the scale as independently as possible. However, volunteers were available to offer limited assistance. Also, volunteers and staff were given a script to explain to those involved the purpose of utilizing the scale as well as the importance of fully completing the scale to have usable data.

Additional data collection tools were designed to be used in the evaluation of this study however, due to a variety of unfortunate circumstances along with the limitations of having staff and volunteers who are not experienced in research and data collection, there

## TR EFFECTS ON WELL-BEING

were barriers that were in place that prevented data collection from being completed in a way that produced useful data. Outside of using the WEMWBS to measure the overall pre and post session data, tools had been selected and put in place to measure the participants' mood both before and after the specific TR session. The intent of that measurement was to determine if the TR session specifically had resulted in a change. With there being two key sections (physical activity and social connectedness) of the week to week interventions, this researcher identified the importance of narrowing down to specifically measure the impact of the TR portion of the program. However, after the first week of sessions, without input from the research team, the ASO facilitators made the decision to no longer use the research tool that was put in place to measure this data. Due to this, there was not sufficient data that could be used to support the research. This tool had been adapted in order to attempt to be more accessible for the facilitators, however, due to the inconsistency of the data collection and communication, this data was deemed unreliable for this study.

Additional tools were used to collect data throughout the session. One of the research tools collected data on not only who attended the session, however, the facilitator indicated whether or not the participant was actively engaged in the various components of the weekly sessions. However, this data was too subjective to be used for this study. A second tool that was used collected week to week feedback from the TR facilitators on the programs that they had selected and asked a variety of questions to indicate whether or not they met their goal for the session, had the facilitator indicate how comfortable they were with the session content, along with what worked during the

## TR EFFECTS ON WELL-BEING

session and what could be improved upon. This information was beyond the scope for this study, however the data collected does provide information on how to continue to enhance the existing sessions moving forward.

Due to the variety of challenges that were faced and the data that was submitted, it was determined that the WEMWBS scale was the only tool that could be utilized to represent the changes in wellbeing for both the participants and the CP's.

### **Design of the Experiment**

As secondary data was utilized for this study, the data collection process that was used for the collection of the primary data is explained in this section. The first step was for the facility coordinators to secure a maximum of 11 couples to participate in the MiM program for each of the six host locations. Before the start of the eight-week program, all participants had to pay the program fee of \$40. There is a variety of required forms that the researchers required the participants to complete. However, for the purpose of this study, the particular form that is being utilized is the 'Participant Self Assessment Questionnaire' question number six as it includes the WEMWB scale pre-test that is used for this research (Appendix H). In most cases all of the paperwork and pre-assessments were completed during the first MiM session. When completing this paperwork, it was suggested to the MiM program coordinators they do not allow a participant and their care partner to complete their assessments together. This process may alter the responses that are given, or, the responses could negatively impact the individual if their loved one replies in a way that may trigger an emotional response. To reduce this challenge, it was suggested that the participants with AD be paired up with someone other than their CP to

## TR EFFECTS ON WELL-BEING

complete the paperwork. Once enrolled in the program, every individual was assigned an identifier code that was created using the code for the location of the program, the individuals' initials and either PWD (person with dementia) or CP (care partner). These identifying codes were kept separate from the rest of the data that was collected and stored at each of the Alzheimer's Society branch locations. This researcher does not have access to the identifying codes.

At the end of each seven-week session the participant and the CP were to complete two post-test analysis. However, only the 'Participant Self Assessment Questionnaire – Post Test' question eight was used for this study as it contained the WEMWB scale post-assessment scores (Appendix I). In addition to the data collected from the participants and their care partner, staff were required to gather and document on other aspects of the program that will not be utilized for this particular study. However, it provides further information for evaluating different aspects of the program.

Facilitators then ensured that all paperwork was coded and sent to the Toronto Alzheimer Society of Ontario (ASO) location so that data can be coordinated and sent to the appropriate researchers.

This researcher was provided with the following data from all six pilot locations for this study:

1. Participant Self Assessment Questionnaire (pre-test): This is the WEMWBS pre test that all individuals had completed at the beginning of the program.
2. Participant Self Assessment Questionnaire (post-test): This is the WEMWBS post that all individuals had to complete at the end of the program.

## TR EFFECTS ON WELL-BEING

Data will be delivered to Brock University by registered mail and secured in advisors locked filing cabinet until approval to use secondary data has arrived.

### **Treatment of Data**

In order to determine whether or not the data supports this studies research questions:

- 1) Does participating in the seven-week TR program of Minds in Motion increase the well-being of participants with Alzheimer's Disease?
- 2) Does participating in the seven-week TR program of Minds in Motion increase the well-being of the care partners of the participants with Alzheimer's Disease?

The pre and post data from the Warwick-Edinburgh Mental Well-Being Scale entered into SPSS and was analyzed through a repeated-measures ANOVA [Group (caregivers vs. partner) X Time (pre vs. post)]. This allows the researcher to identify if there was a significant difference within-subjects and between-subjects. A repeated-measures ANOVA is able to “take account of systemic difference between subjects, which usually lead to more powerful tests” (Norman & Streiner, 2008, p. 109). This method will allow the researcher to determine if there is not only an increase or decrease in well-being from pre to post assessment, but it is also be able to demonstrate the difference between the two groupings of care partners and the persons with dementia. The use of this method is a stronger approach than conducting the t-test and will allow for more variables to be analyzed to determine if completion of the MiM social connectedness program results in an increase in wellbeing and the rate of difference between the CP and the PWD. If a significant group  $\times$  time interaction occurred, paired

## TR EFFECTS ON WELL-BEING

samples t-tests will be used as post-hoc tests to determine significant time differences within each group.

### **Conclusion**

Feedback from this section aims at informing the researcher if there are similarities or differences between the individuals well-being related to completing the program. The analysis answers the questions of whether the TR program of Minds in Motion increased the well-being of participants with Alzheimer's Disease; of whether the TR program of Minds in Motion improved the well-being of care partners. If this is a program that produces significant positive effects for the participants, it then may be used as a cost-effective evidence-based plan that could be administered by the Alzheimer's Society.

## **Chapter 4**

### **Results**

The purpose of the study is to examine an effect of a Therapeutic Recreation program on enhancing overall well-being through the use of activities that build skills and enhance positive emotion for individuals with Alzheimer's Disease and their care partners. This question was answered by acquiring secondary data of participants and care partners (CP) from a previous study. That study had used the Warwick Edinburg Mental Wellbeing Scale (WEMWBS) to gain insight regarding wellbeing of participants. From this data set, a total of 333 Pre-Tests and 287 Post-Tests were completed. Only 234 participants had successfully completed the both the pre and post- test for this research. Of these 234 participants who completed all data required, 111 (47%) of these duals were care partners (CP) and 123 (53%) were persons with dementia (PWD). Data had to be used from both the first and second round of the MiM program in order to have enough data to analyze.

### **Hypothesis Statement**

1. Persons with dementia (PWD) are expected to increase significantly in their well-being from pretest to posttest measurements.
2. Care Partners (CP) for individuals with AD are expected to increase significantly in their well-being from pretest to posttest measurements.

## TR EFFECTS ON WELL-BEING

### Testing the Hypothesis

#### *Person with Dementia*

Persons with dementia are expected to increase significantly in their well-being from pretest to posttest measurements.

This data was analyzed through a repeated-measures ANOVA [Group (caregivers vs. partner) x Time (pre vs. post)]. There was not a significant difference between the pretest scores ( $M = 53.34$ ,  $SD = 8.50$ ) and the posttest scores ( $M = 54.39$ ,  $SD = 8.70$ ), indicating a lack of support for this hypothesis,  $F(1, 232) = 2.15$ ,  $p = .14$ . Additional evidence not supporting this hypothesis comes from the non-significant interaction,  $F(1, 232) = 1.67$ ,  $p = .19$ . As can be seen from the WEMWB scores in Table 1, there was a slight increase in well-being for persons with dementia, however, not enough of an increase was present to make the results statistically significant.

Table 1  
*Descriptive Statistics for WEMWBS Scores*

	CP			PWD			Total		
	<i>M</i>	<i>SD</i>	<i>n</i>	<i>M</i>	<i>SD</i>	<i>n</i>	<i>M</i>	<i>SD</i>	<i>n</i>
Pre	54.90	8.46	111	51.93	8.32	123	53.34	8.50	234
Post	55.02	8.84	111	53.82	8.57	123	54.39	8.70	234

The non-significant interaction indicates there was no difference in an increase in wellbeing for either group. Therefore, the  $H_{O1}$  is rejected.

#### *Care Partners*

Care Partners for individuals with AD are expected to increase significantly in their well-being from pretest to posttest measurements.



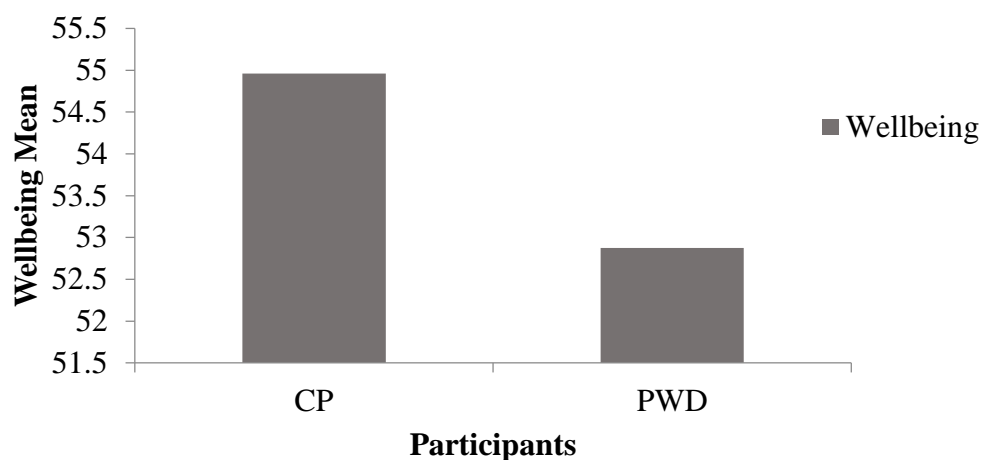
## TR EFFECTS ON WELL-BEING

This hypothesis was examined using the same repeated-measures ANOVA [Group (caregivers vs. partner) x Time (pre vs. post)] as above. As previously noted, there was not a significant difference between the pretest scores and the posttest scores, indicating a lack of support for this hypothesis as well. Additional evidence not supporting this hypothesis comes from the non-significant interaction. Although there was an increase in well-being slightly higher than that of the PWD (as can be seen in Table 1), there was not enough of an increase was identified to make the results statistically significant. The non-significant interaction indicates there was no difference in an increase in wellbeing for either group. Therefore, the  $H_{O2}$  is rejected.

### **Additional findings**

Although there was no significance for the within-subject effect of change from pre to post-test score, the ANOVA did reveal a significant between-subjects effect,  $F(1, 232) = 5.58, p = .019$ . As can be seen in Figure 1, data gathered from the participant surveys indicated that CP had a higher wellbeing score ( $M = 54.96, SD = 7.04$ ) than PWD ( $M = 52.87, SD = 6.48$ ). This result indicates that overall CP's have indicated that they have a higher level of wellbeing then their loved ones that were participating in the program with them.

## TR EFFECTS ON WELL-BEING



*Figure 1.* Between-subject effect demonstrates that care partners (CP) had higher overall wellbeing than persons with dementia (PWD).

Although not hypothesized, the results in Figure 1 indicate that overall CP's have a higher level of wellbeing than their loved ones that were participating in the program with them. The data set in this study identified that CP's start with a higher wellbeing score than their loved ones. This higher level of wellbeing appears to be external to the program being offered. Based on the research from the Alzheimer's Society of Canada Website (2015) and Lowi-Young (2014), it was anticipated that CP would have lower wellbeing scores from pre-test to post-test than the PWD due to the various stressors and burdens that CP face while caring for a PWD. However, this was not the case, and possible reasons for this difference will be discussed in the next chapter.

The next chapter will also inform the reader of anecdotal information about the program. There will be discussion and implications of the use of secondary data. The chapter will end with a commentary of what was learned from this experience.

## **Chapter 5**

### **Discussion and Conclusion**

#### **Overview**

The Public Health Agency of Canada (2010) continues to emphasize the various challenges that Canada is starting to, and will continue to experience as our population continues to age. With this aging population the increased presence of AD and other related dementias puts a significant amount of pressure on not only families, but the Country as a whole. Prince, Bryce and Ferri (2011) identified the importance of utilizing innovative interventions to slow or prevent the progression of AD. With this, researchers and community agencies continue to seek new approaches to keep both body and mind healthy in order to addressing this rising crisis. This researcher saw value in utilizing Hood and Carruthers (2007) Leisure and Wellbeing Model as a TR lens to deliver the program. It allowed the program to utilize various approaches in order to strive towards a distal goal of well-being. Utilizing this approach allows the facilitators to select and deliver activities that would most benefit the participants. Bradford (2016) identified that individuals who received dementia-specific support were “50% less likely to move into a care home, 42% less likely to spend time in hospital and more likely to rate their quality of life positively” (p.22). The Alzheimer Society of Canada (2010) were able to identify the growing pressure that this aging population had for CP and highlighted the benefits of including CP in programs in order to attain the information and support that they require. Unfortunately, this research project did not find statistics with significant results due to a variety of potential challenges that were experienced in this process.

## TR EFFECTS ON WELL-BEING

### **Summary**

This research project looked at a newly developed program that was designed using a TR framework to increase the overall well-being for individuals in the early to mid-stages of Alzheimer's Disease or other related dementias. Although the results were not found to be significant, there was an increase in well-being from the pre and post-test WEMWBS assessment. Through further analysis of this program, more data may be available to have a clearer picture of the strengths of this program.

This research aimed to align with a significant amount of researchers who identified the strain that CP face in supporting a loved one with AD. Pinquart and Sorensen (2003) identified that there are significant differences in both psychological health and physical health of those who are caregivers compared to those who are not caregivers. Ferrara et al. (2008) went on to discuss how it is "vital to promote interventions [that are] able to reduce the strong impact that the AD patient has on his/her caregiver; these initiatives should improve the quality of life of the [AD] patient"(p.97). This project attempted to build on this approach to further support PWD and their CP. As previously mentioned, this program was anticipated for those in early to mid stages of AD and other related dementias, however, there was no measurement to indicate the level of dementia. Ferrara et al. (2008) discuss how the "quality of life of the informal caregiver closely correlated with the severity of the behavioral disorder and the duration of the disease" (p.97). This emphasizes the importance of early intervention.

This study was aimed at early intervention for PWD, however, the phase of AD or the time the CP had been caring for the person was not known. The slight increase in

## TR EFFECTS ON WELL-BEING

wellbeing that emerged in this study could potentially have been much greater if the various levels of AD progression could have been taken into account. Being able to factor out the variance that came from the various AD levels and the total time of caring by the CP would have allowed for a clearer picture of the effectiveness of this program.

### **Unpredicted findings**

It is important to bring attention to the unpredicted finding that this study found when looking at the between-subject effect showing that CP's have a higher level of wellbeing than their loved ones. Based on the previous literature which outlines the growing strain that caring for a loved one with AD has on CP, this outcome was unanticipated due to the significant stress (social, emotional, financial, etc.) that is placed on CP who are caring for a PWD (Wong, 2014; Alzheimer Society of Canada, 2010; Lowi-Young, 2014; Minds in Motion, 2014). At this time the reason for this outcome is unknown, however it is potentially important to also focus on the benefits that being a CP has for members of the community. Becoming a CP is a significant change in someone's life, however it is important to identify the value that individuals can gain from the feeling of giving back to their loved one. Some CP, especially those invested in their loved ones life, like to seek out additional programs such as MiM to enhance their wellbeing may actually find significant meaning in being able to support and repay some of the kindness that their loved one may have given them throughout the years. As well, this study identifies that its main participant focus was for individuals in early to mid stages of AD or other dementias. It is important to outline that this may be a particularly difficult period of transition for these individuals. The research above explains how

## TR EFFECTS ON WELL-BEING

PWD are gradually impacted by the effects of this disease (Alzheimer's Society of Canada, 2014; Shan, 2013; Holland, 2013; Alzheimer Society of Canada, 2010; Cohen, 1999). This decline in functioning for PWD possibly has more of a significant impact on the wellbeing of PWD versus the impact that CP experience in this transition. Additional research could explore this finding further. Additional research could explore this finding further, as McFannen and McFadden (2012) indicate that "true friendship can offset some of the despair associated with dementia...a call to arms for a more caring, related society—a flourishing community—from which all can benefit, and in which all have a part to play", thus indicating that the creating of these social networks through the social connectedness program could be the beginning of the flourishing community needed for the AD and CP (p.560).

## Discussion

Overall, this research project attempted to evaluate a large number of items over a short period of time in order to stay on target and meet grant required timelines. With these short time lines, decisions were made and processes were put in place without proper communication, support and clarity of all partners involved. With this, there are a variety of reasons that could contribute to why the hypotheses were not supported. For this program, there were a number of smaller research projects that were compiled together to make one evidence based research project. The complexity of this research project placed pressure on the ASO facilitators, when many of them did not have any previous experience in research delivery or evaluation.

## TR EFFECTS ON WELL-BEING

### *Participants*

One significant factor that could have had an impact on the outcome of this research project could have been the participants who were selected to be involved in the program. Prince, Bryce and Ferris (2011), along with the Department of Health (2009) support the concept that there are benefits to early interventions for those with AD and other dementias. With this information, it was determined that the MiM program would be intended for those in the early to mid stages of AD and other dementias. However, based on the feedback from some of the MiM locations, it was identified that some participants may have been further along in their diagnosis, as some PWD were not able to fully participate in the program and/or evaluations. For this research project, it was determined that there would be no assessment tool used to determine whether the MiM program would be a suitable fit for the PWD. Involvement in the program was left to the discretion of the facilitator.

Having individuals who are further along in their illness could have impact the outcome of this study as it is difficult to determine if the outcomes that were found were due to the programming, or if it was due to the participants' ability to fully participate in the sessions that were offered. As well, this could be a leading factor in the PWD ability to complete evaluation tools. Some PWD struggled with, and did not accurately complete the evaluation tools or had CP who could have supported and influenced their responses, which meant that their data may not reflect actual outcomes. Moving forward with future research on this program, it would be important to have some form of assessment or key indicators in order to determine that the PWD are in early to mid

## TR EFFECTS ON WELL-BEING

stages of AD or other dementias in order to get an accurate reflection of the impact of this program.

### *Facilitators*

As previously mentioned, the ASO facilitators for this program were given a large role in all aspects of the participant recruitment, program delivery, program evaluation and community relations. The ASO facilitators and volunteers were given the challenge of delivering this new program and were the front line presence to field all questions and to support and collect data for this project. One of the significant learning tasks that this research project faced was how the data collection process was completed. The ASO program staff and volunteers who do not have training and understanding of evidence-based research did not completely follow through on data collection. There was not buy-in from all locations to offer and evaluate the program with the provided guidelines. The first two rounds of this program were a significant learning curve for the facilitators, as they were not only working to become more familiar with the Social Connectedness sessions, but with the required paperwork. With limited resources available, facilitators sometimes had challenges with meeting the needs of the participants, meeting the requirements of the program delivery, as well as ensuring secure and controlled data collection process. There is no guarantee that CP did not influence the responses of the PWD in the data collection process.

In terms of the Social Connectedness portion of the program, facilitators were only given a few hours to be introduced to the program content, to become familiar with what was expected of them in terms of program delivery and evaluation tools and to ask



## TR EFFECTS ON WELL-BEING

any questions that they may have for the researcher before heading back to their communities to implement the program. Moving forward, it is recommended that more time be allotted to the training of the facilitators and volunteers in order to go over all aspects of the program. This would allow the facilitators to experience the sessions to be implemented and to get experience facilitating sessions in order to obtain feedback on how to further improve their facilitation skills of the provided programs. This would also allow the researcher to outline the facilitators ability to adjust certain aspects of the programs in order to make them more accessible to their participants (e.g., Use a bag instead of a sock), however ensuring that the content of the program remains the same. A longer training time would allow facilitators to get some hands on practice and allow for a further understanding of both the TR infused sessions as well as the evaluation tools.

Throughout the implementation of the MiM program, there were other tools (e.g., Teleconference, webinar, etc.) that were used during parts of this project to provide further information or explanation, however prior preparation could have allowed this to happen more often. For the most part, this researcher was excluded from the program once the MiM program was in the implementation phase. In future research projects, it would be beneficial for the researcher to provide support on an ongoing basis. This could take place in weekly discussions to review challenges and to provide an overview/reminder of the key objectives for the upcoming sessions. As well, additional onsite visits could have been used to ensure programs were being delivered appropriately in order to ensure quality. As it was discovered that occasionally, facilitators were changing the programs all together, which could have affected the research outcomes.

## TR EFFECTS ON WELL-BEING

When reviewing this research project, the researcher had to determine if the Social Connectedness program could be considered a TR program as the title of this research project suggests. Ultimately, the program cannot be considered a TR program as it was not facilitated by TR professionals. Through the use of ASO facilitators, this researcher is unable to ensure that the program was delivered and facilitated utilizing TR practice. The tools were put in place to support the facilitators in delivering the programs, however a two hour training and resource guide is not sufficient for this program to be considered a TR program. In the future researchers should be cautious of using the data from this study to reflect TR outcomes.

### ***Community Based Research***

Singha (2012) emphasized the importance of bringing the programs to communities in order to make it accessible and to ensure that people have access to care in places where it is needed. However, through the quick implementation of the MiM program within a variety of communities, there were some key faults which prevented the research project from having a more successful community based research project. Moving forward, it is important that the researcher involve the community partners in the research design, specifically in terms of the program/ paperwork/ evaluation expectations.

The original plan of this study was to look at the social connectedness portion of the MiM program to determine if the seven-week program based on the TR framework of the LWM (Hood & Carruthers, 2007) was able to increase the participants' positive emotion and overall well-being. Initially, this researcher was going to look at the results of the WEMWBS pre and post-test results, but the original plan was to also look at the

## TR EFFECTS ON WELL-BEING

results from the Check in List (CIL). The CIL was a modified assessment that was to be completed by the participants before and after the social connectedness section of the program. Unfortunately, ASO and the facilitators had decided to stop using the CIL tool within the first week of the program being implemented without the consultation of the researcher. Having access to this data would have assisted the researcher in identifying the impact that each session had on each individual throughout the seven weeks. A modified version of the assessment was created for the MiM program based on the feedback and needs of the ASO and the facilitators. Due to the fact that this data did not exist for the first round of data and was administered inconsistently for the second round of data, this researcher decided not to use the CIL as an assessment tool for this research project. Future studies could look at the CIL as a tool to determine which sessions have a greater positive impact on the participants' positive emotion and can be used to identify which session to replace.

If the partners were involved in determining this process, the facilitators would have been able to identify any challenges that they foresee, along with allowing for an opportunity to identify any supports that they may require in order to be successful. Having prior conversations would have allowed the CIL process to have been worked out before hand, resulting in more data available for the first two rounds of this program.

Without including the partners (ASO facilitators) into the design and development of this program, the facilitators did not necessarily have an invested interest. Some facilitators faced this program with resistance as they were given additional tasks to do and were being told how to run their programs. Less resistance and more support of the

## TR EFFECTS ON WELL-BEING

program could have occurred if the time was taken to inform the facilitators on the importance of evidence based research and what benefits could come of it (increased funding, increased ASO support, increase in resources, increase in community health, etc.). Having these prior discussions would have allowed for more shared decisions, which could have prevented ASO facilitators from making the decision to discontinue using a key evaluation tool without consulting with the researcher. With the facilitators having such a significant role in the delivery and evaluation of this research project, it is important to get their support for the full process (Community-Based Research Canada, 2016). Without their support of the program, it is difficult to get the community participants to understand the full benefits of their involvement of all aspects of the research project. Many of the participants had a hard time seeing the benefits of completing all of the paperwork that was required of the weekly sessions. Many participants expressed that they liked the programs, however they had a negative experience with all of the evaluation requirements for both the physical and Social Connections portions of this research project. It is importance to keep a healthy power balance between facilitators and researchers in order to work together to form functional and beneficial solutions (University of Victoria, 2011).

### *Secondary Data*

This research project relied on the use of secondary data that was collected for the MiM program by the University of Waterloo. Due to the time sensitivity of the MiM program, this was the most suitable option for moving forward. However with utilizing secondary data, there are some challenges that evolve. Through using secondary data,

## TR EFFECTS ON WELL-BEING

researchers are utilizing data that is available. For most situations, input in the data collection process is not accessible, so researchers who use secondary data only have access to the data that is available, no further questions are able to occur. Tripathy (2013) and Bulmer (1980), believe that secondary data is filled with errors and could be deemed inaccurate. There is a strong belief that we can use data in many ways, however the most important part of the process relies on those collecting the data. If the front line data collection is not done in an efficient and accurate manner, then the data outcome may then be irrelevant as it could be flawed. This is one of the challenges that this research project struggles with as the data collection process relied on the ASO facilitators to collect, however as it was explained after the data collection process, that there were many inconsistencies and many challenges with communication, support and completion of the tools. Smith (2008) goes on to further explain the challenges of utilizing numbers to reflect the quality of life of individuals, and using the numbers identified to represent reality. There are challenges in quantifying items such as quality of life. Through only utilizing quantitative data for this research, there could be a gap in knowledge as not all individuals, especially those experiencing AD are able to quantify their feelings appropriately. As well, this process would rely heavily on the support of the facilitators to assist with the data collection process, which could have caused errors to occur in the original data collection process.

Overall, regardless of the various challenges that this research project faced, there was an increase in well-being for both the CP and the PWD. Unfortunately the increase was not enough of an increase to indicate significance. This could be due to a variety of

## TR EFFECTS ON WELL-BEING

the reasons listed above. This outcome indicates that there is value in future research continuing to explore the outcomes of including CP's in programs with their loved one. However, it is important to take into account the key learning's from this research project.

As well, it is important to note that although this study utilized secondary data, that the researcher was involved in the initial set up of the program.

### *Measurement*

In reviewing this research project, this researcher had to determine if the measurement tool that was selected actually measured what it was supposed to. The measurement tool was deemed appropriate for this population and was selected under a tight timeframe, however in hindsight this measurement tool does not necessarily measure what it was anticipated to measure. With only having a pre and post measurement tool, this researcher is unable to determine if the outcomes are directly related to the Social Connectedness portion of the program. The outcomes from the pre and post measurement are a reflection on the outcomes of both the Physical Activity and the Social Connectedness portions of the programs. Another area of concern when reviewing the measurement tool is that the Warwick Edinburg Mental Well Being Scale is designed to assess mental well being specifically. This means that this tool cannot be used to determine the effects of overall wellbeing for both participants with AD and their CP. Another challenge that was identified in selecting this measurement tool for this program specifically is that overall, the research project was expecting to measure change in well being during a seven week program, which is significantly ambitious and not

## TR EFFECTS ON WELL-BEING

necessarily attainable. Future studies should look at smaller sections when measuring change, such as social relatedness, meaningful relationship building, sense of community, etc. Future studies should ensure that they have a process in place to measure positive emotion and social building related measures, or other more appropriate tools.

### *Program Design*

Although this researcher was unable to collect the necessary data required to measure the outcomes of the specific programs that were delivered, it is still important to review and discuss the overall program design. Initially the Social Connectedness programs were set up and designed to give the facilitators a choice of three to six programs to pick from each week. However, with further review and reflection, the way that the program is currently designed does not actually set the program up to be as evidence based research ready as it can be. With having a variety of facilitators at a variety of locations being able to select from a variety of programs, it is difficult to actually measure and determine if the program works. In order to prepare this research project to be more evidence based research ready, we need to further review the format of the program design.

Moving forward, the researcher needs to make changes to how the Social Connectedness portion of the program is organized and facilitated. The Social Connectedness portion of the program needs to be tightened up to be more consistent regardless of where the program is being offered. There needs to be a more specific process for the programs to be offered and it needs to be consistent across all locations. As well, in order to ensure that programs are being delivered in a consistent and

## TR EFFECTS ON WELL-BEING

measurable manner, it is important that TR practitioners are delivering the Social Connectedness portion of the program at all locations. This will ensure that all sessions are accurately utilizing a TR framework.

In terms of the program content and focus, the Social Connectedness programs should be reviewed and adjusted utilizing the LWM Guidelines that Hood and Carruthers (2016) published. With this the overall goal of the Social Connectedness program needs to be assessed and adjusted. As previously mentioned, the overall goal of increasing wellbeing is not a reasonable goal for a seven week program. Instead of looking at the distal goal of wellbeing, the program should be designed to look at a medial goal in the design of the content as it is more attainable. With this, the individual programs would also have to be reviewed and designed to align with the new goal that is identified, ensuring that it is following LWM best practices. This will also assist in the programs being offered more consistently across all locations.

The final area for review in terms of program design would be to add the evaluation tool into the lesson plan. This research project faced significant challenges while implementing the evaluation portion of the project. However, through adding it to the lesson plan, it would hide the formal assessment process and would potentially have less push back and less of an impact on the participants.

### ***Lessons Learned***

Although this research project did not have a favorable outcome, this outcome encouraged the researcher to further analyze all aspects of this research project in depth utilizing various lenses to make recommendations. This research project provides a lot of



## TR EFFECTS ON WELL-BEING

information and recommendations for future researchers to use in their own research projects moving forward.

With the challenges and lessons learned in this study, this program has the possibility of being significantly stronger when moving forward. The research shows that AD will continue to have a significant impact on our country unless something is done. With further revisions of this program and applying the recommendations, moving forward this program could help lessen the impact on persons with AD, their CP and the community. When moving forward with future research on this program it is important to take the time needed to set the program up properly, ensuring that all stake holders are involved from the beginning and that the assessment tool is the most appropriate for the intended outcome of the program. In order to re-build faith from the ASO in support of this program I think it is important show that greater growth and improvements can come from a negative outcome. This researcher now sees that there is significant value in conducting a case study in order to implement the program as it was intended, utilizing a TR practitioner in the delivery of the Social Connectedness program. This would allow for a comparison to take place that has the potential to outline the benefits of utilizing the most appropriate resources moving forward. This would allow the ASO to ensure that their funds are being used in the most effective manner.

Having an unsuccessful outcome does not mean that the program is bad or that it will never work, it just means that moving forward some revisions need to be made. There is always room for growth and improvements and this researcher hopes that the

## TR EFFECTS ON WELL-BEING

ASO will continue to be interested in further exploring the potential benefits that this program still has to offer.

### **Recommendations**

In terms of research design, I would suggest the following recommendations this research project if it were to be implemented in the future. Initially there was a lot of pressure put on the facilitators to not only collect the data for one research project, but for two. It is important to ensure that the research requirements and expectations are not negatively impacting the participants' experience. It may be beneficial to break this research project down into smaller sections (e.g., Physical and Social Connectedness) in order ensure that the evaluation requirements are reasonable for the facilitator and for the participants. As well, there may be value in exploring a mixed method approach in order to include additional information in a method that may be more accessible for participants. This will also allow the research to have the ability to capture benefits that quantitative data is unable to access for a variety of reasons (language, comprehension, etc.).

In addition to re-evaluating the data collection method, it is also important to consider using a sample/control group to be able to have a reliable baseline to compare outcomes. As well, based on the assessment tools that were utilized, there were limitations on how the data could be analyzed. Moving forward, it would be beneficial for the researcher to have access to demographic information in order to analyze trends in age, gender, etc. Demographic information was excluded from this research project as ASO requested that demographic information not be a part of the research project as it

## TR EFFECTS ON WELL-BEING

could be a barrier to participation for some individuals. As well, future research should consider looking at not only at the PWD and the CP separately in the data analysis process, but also consider looking at the paired data to analyze any trends that may exist between the two individuals progression through the program together.

The social connectedness portion of the MiM pilot program, utilized the therapeutic recreation framework of Hood and Carruthers (2007) Leisure and Well-being Model (LWM). This model was new to the population (CP and PWD) at ASO.

Although the results of the MiM program were not statistically significant, it does not rule out the value of the LWM perspective of TR for this population. There is benefit in investigating the advantages of the LWM for individuals who are further progressed in their disease to determine if it is a suitable/ most beneficial approach for CP and PWD together. Overall, the holistic approach of the LWM in working with PWD and their CP had many strengths, such as being able to adjust programming to meet the needs of the CP and PWD. Future research could further explore the value of using the LWM in working with this population. Qualitative data may have been able to indicate some of the non-statistical benefits. As well, further evaluation of the social connectedness program could also enhance the experience/ outcomes from participants.

It is important to continue to conduct further research on the existing programs as well to reflect and determine if it is in the appropriate order. The British Columbia MiM program provided feedback on the types of activities that the PWD and CP were doing during the Social Connectedness portion of their program. This researcher then took some of the suggested activities and added a TR lens to implement and foster meaningful

## TR EFFECTS ON WELL-BEING

activity for the PWD and CP. Moving forward, it would be valuable to further explore new research that outlines TR programs that utilize the LWM as a lens that can demonstrate successful outcomes for an aging population. Through using existing programs that are supported by evidence based research, could allow facilitators to have more activities to access in order to deliver a stronger overall program to implement.

Since the initiation of this project, Hood and Carruthers (2016) have developed a guide to best direct TR's in effectively designing programs utilizing the LWM. Future recommendations would be to re-review the content of the program and adjust to align with the guidelines to best execute the TR programs.

## Conclusions

Although the means were in the direction of increase, they were not found to be statistically significant, however, it was not detrimental to have CP participate in community programs with their loved one as the well-being for both CP and PWD slightly increased, whereas well-being for the CP increased more than the PWD.

Typically programs are offered separately for CP's and PWD, this research shows that there is some value in having the CP and PWD participating in the program together. As identified by Alzheimer Society of Ontario (2015), "94% of participants are actively engaged in the Therapeutic Recreation and social connectedness component" (p. 12). Based on the feedback that was provided by the ASO project manager, the participants were not only engaging in these activities at the program, but were also able to enjoy either the activities or the recollection of the activity. The program manager shared some feedback from the Sault Saint Marie location "one of the participants was hesitant to play

## TR EFFECTS ON WELL-BEING

jenga but once he did he really enjoyed it and then the next week brought in a picture of his son playing it back in the day!” (F. White, personal communication, May 8, 2015). It is important to continue to invest in community programs that meet the needs of both the CP and PWD to promote health and well-being in a community setting. Other outcomes from this program identified a decrease in social isolation as well, feedback outlined that “79% report that they are seeking other opportunities to participate in community programs as a result of MIM.” (Alzheimer Society of Ontario, 2015). Further feedback from the staff indicate “...to see the participants - just the engagement, the change from the first week to the last week, the fun, the laughter, the opportunity for participants and their care partners to do something enjoyable and fun and relaxing together” (Press release 2015, ASO). This program allowed the PWD and their CP to not only connect and share these experiences with each other, but also other individuals who are experiencing the same challenges. Both PWD and CP were able to connect and share with others, “53% of participants state that they have developed a new relationship through the group that they expect to continue” (Alzheimer Society of Ontario, 2015). With further adjustments, this program has the potential to further develop into a program that can work towards providing a needed community based program to help address and hopefully lessen the impact of AD on our communities.

More research on the delivery of the program and determining which activities are more successful could enhance the quality of the program moving forward. As well, I think it would be beneficial to offer this program in different settings such as long term care facilities to collect evidence-based research to further determine if there are benefits

## TR EFFECTS ON WELL-BEING

for our aging populations. In moving forward I would recommend having TR professionals deliver the Social Connectedness portion of the program when possible. As well, it would be beneficial to have researchers involved in the data collection process to ensure that communication is consistent and that paper work is supported and collected accurately.

It would be helpful to further review the remaining data that is available (e.g., facilitators session by session feedback) to continue to further develop the program based on the feedback that was provided. Additionally, it would be useful to look at later rounds of data to analyze the CIL assessment to determine on a session-by-session basis which programs had the most significant impact. This too, will allow the researcher to determine which programs are most successful in increasing positive emotion and well-being.

Additionally, it is important to capitalize on the unexpected finding that the study identified in terms of CP having an overall higher rating of wellbeing than the PWD. This unexpected, yet important finding could be used as a baseline to investigate how to lessen this impact for PWD. In lessening the impact that this disease has for PWD, this will not only have the potential to increase the overall wellbeing for PWD, but their CP as well. It is important to emphasize the need for further research on the importance of early interventions to help families (both CP and PWD) to prepare for this potential life changing disease in order to decrease the potential impact that this disease could have on families, communities, economy, etc.

## TR EFFECTS ON WELL-BEING

Overall this program is in the early stages of development, through further analysis and changes, this program could play a role in enhancing the well-being of person's with dementia and their CP's. It is still believed that modifications could facilitate a cost effective intervention for families. There is a need for more training in the delivery of the program, as well as in the appropriate research protocol. This would be beneficial to see outcomes more clearly.

This has allowed this researcher a new perspective regarding applied research. The difficulty that occurred in trying to explain the procedures and how important it was to follow them explicitly was not fully anticipated. Individuals personal judgement and possibly comfort with the material appeared to take precedence over the research. As indicated, a learning experience which from this time forward I will take into account with other endeavors.

## TR EFFECTS ON WELL-BEING

## References

- Abd El-Kader, S. M. (2011). Role of aerobic exercise training in changing exercise tolerance and quality of life in Alzheimer's disease. *European Journal of General Medicine*, 8(1), 1-6.
- About Therapeutic Recreation (2014, June 14). Retrieved from <https://www.trontario.org/about-therapeutic-recreation>.
- Alzheimer's Society of Canada (2015). *Brain health*. Retrieved from <http://www.alzheimer.ca/en/About-dementia/Brain-health>
- Alzheimer's Society of Ontario. (2015). *Minds in motion: A physical activity and brain stimulation program for people with dementia and their care partners [PowerPoint slides]*.
- Ambrose, R. (2014). *National dementia research and prevention plan: Ministerial statement*. Government of Canada: Minister of Health.
- Arifini, W, N. (2014). Calculating standard deviation of difference for determination of sample size for planned paired t-test analysis. *Educational Resources*, 6(2), e62-e64. DOI:10.5959/eimj.v6i2.252.
- Belfry, S., Fitzgerald, C., McAdam, L., Paterson, D, H., & Van Gorp, D. (2014). *Dementia and exercise: Implementation of the Alzheimer Society of Ontario's Minds in Motion pilot project*.
- Bulmer, M. (1980). Why don't sociologists make more use of official statistics? *Sociology*, 14(4).



## TR EFFECTS ON WELL-BEING

- Carter, M.J., Van Andel, G.E., & Robb, G.M. (2003). *Therapeutic Recreation: A practical approach* (3<sup>rd</sup> ed.). Prospect Heights, Illinois: Waveland Press, Inc.
- Cooper, C., Katona, C., Orrell, M., & Livingston, G. (2008). Coping strategies, anxiety and depression in caregivers of people with Alzheimer's disease. *International Journal of Geriatric Psychiatry*, 23, 929-936. DOI:10.1002/gps.2007.
- Department of Health. (2009). *Living well with dementia: A National dementia strategy*. London, UK: Department of health. Retrieved from [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/168220/dh\\_094051.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/168220/dh_094051.pdf)
- Elwood, C. (1999). *Alzheimer's Disease: Prevention, intervention and treatment*. Lincolnwood, Illinois: Keats Publishing.
- Fauth, E., Hess, K., Piercy, K., Norton, M., Corcoran, C., Rabins, P., Lyketsos, C., & Tschanz, J. (2012). Caregivers' relationship closeness with their person with dementia predicts both positive and negative outcomes for caregivers' physical health and psychological well-being. *Aging & Mental Health*, 16(6), 699-711.
- Ferrara, M., Langiano, E., Di Brango, T., De Vito, E., Di Cioccio, L., & Bauco, C. (2008). Prevalence of stress, anxiety and depression with Alzheimer caregivers. *Health and Quality of Life Outcomes*, 6(93), 93-99. DOI: 10.1186/1477-7525-6-93.

## TR EFFECTS ON WELL-BEING

- Foot, D. K., & Stoffman, D. (1997). *Boom, Bust and Echo: How to profit from the coming demographic shift in the 21<sup>st</sup> century (1<sup>st</sup> ed.)*. Toronto. Macfarlane Walter & Ross.
- Fredrickson, B. (n.d). *Positivity*. Retrieved from <http://www.positivityratio.com/single.php?taken=1&p1=-1&n1=-1&n2=3&p2=0&n3=0>.
- Fredrickson, B. L. (2000, March 7). Cultivating positive emotions to optimize health and well-being. *Prevention & Treatment*, 3, Article 0001a. Retrieved January 12, 2015, from <http://media.rickhanson.net/home/files/papers/CultPosEmot.pdf>
- Fredrickson, B., & Joiner, T. (2002). Positive emotions trigger upward spirals toward emotional well-being. *Psychological Science*, 13(2), 172-175.
- Hood, C. D., & Carruthers, C. (2007). Building a life of meaning though therapeutic recreation: The Leisure and Well-Being Model, part I. *Therapeutic Recreation Journal*, 41(4), 276-297.
- Hood, C. D., & Carruthers, C. (2011). Mindfulness and well-being: Implications for therapeutic recreation practice. *Therapeutic Recreation Journal*, 45(3), 171-189.
- Hood, C. D., & Carruthers, C. (2016). Strengths-based TR program development using the leisure and well-being model: translating theory into practice. *Therapeutic Recreation Journal*, 50(1), 4-20.
- Johnson, J.D., Witlatch, C.J., & Menne, H.L. (2014). Activity and well-being of older adults: Does cognitive impairment play a role? *Research on Aging*, 36(2), 147-160.

## TR EFFECTS ON WELL-BEING

Kolanowski, M. A., Beuttner, L., Costa, T. P., & Litaker, S. M. (2001), Capturing

interests: Therapeutic recreation activities for persons with dementia. *Therapeutic Recreation Journal*, 35(3), 220-235.

Kunstler, R. (2002). Therapeutic recreation in the naturally occurring retirement community (NORC): Benefitting “Aging in Place.” *Therapeutic Recreation Journal*, 36(2), 186-202.

Leahey, A., & Singleton, J. F. (2011). Utilizing therapeutic recreation to empower persons with Alzheimer's in a day center. *Therapeutic Recreation Journal*, 45(2), 135-146.

Living with Dementia. (2015, January 1). Retrieved February 21, 2015, from <http://www.alzheimer.ca/en/Living-with-dementia>

Lowi-Young, M. (2014). *Partnering to strengthen Canada's future. A national dementia plan*. Alzheimer Society of Canada: Chief Executive Officer.

McFadden, S. H., & McFadden, J. T. (2012). Aging together: Dementia, friendship and flourishing communities. *Journal of Gerontological Social Work*, 55(6), 560-562.

Measuring the impact of your work on mental wellbeing: Using WEMWBS to measure the impact of your work on mental wellbeing. (2012, September). Retrieved from <http://www.champspublichealth.com/writedir/1cfcWEMWBS%20practitioner-based%20user%20guide%20for%20evaluation%20Sept%202012.pdf>.

## TR EFFECTS ON WELL-BEING

Minds in Motion: A physical activity and brain stimulation program for people with

dementia and their care partner. (2014, June 14). Retrieved from

<http://www.alzheimer.ca/en/on/We-can-help/Minds-In-Motion/What-is-Minds-in-Motion>.

Norman, G. R., & Streiner, D. L. (2008). *Biostatistics: The bare essentials* (3<sup>rd</sup> ed.).

Shelton, Connecticut: People's Medical Publishing House.

Orgeta, V., Sterzo, E. L., & Orrell, M. (2013). Assessing mental well-being in family carers of people with dementia using the Warwick-Edinburg Mental Well-Being Scale. *International Psychogeriatrics*, 25(9), 1443-1451.

Owram, D. (1996). *Born at the right time: A history of the baby boom generation*.

Toronto: University of Toronto Press.

Pinquart, M., & Sorensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychology and Aging*, 18(2), 250-267.

Prince, M., Bryce, R., & Ferri, C. (2011). *World Alzheimer report 2011: The benefits of early diagnosis and intervention*. London, UK: Alzheimer's Disease International.

Retrieved from <http://www.alz.co.uk/research/WorldAlzheimerReport2011.pdf>.

Public Health Agency of Canada. (2010). *The Chief Public Health Officer's report on the state of public health in Canada 2010*. Retrieved from [http://www.phac-](http://www.phac-aspc.gc.ca/cphorsphc-respcacsp/2010/fr-rc/cphorsphc-respcacsp-06-eng.php)

[aspc.gc.ca/cphorsphc-respcacsp/2010/fr-rc/cphorsphc-respcacsp-06-eng.php](http://www.phac-aspc.gc.ca/cphorsphc-respcacsp/2010/fr-rc/cphorsphc-respcacsp-06-eng.php).

Simone, P.M., & Haas, A.L. (2013). Frailty, leisure activity and functional status in older adults. *Clinical Gerontologist*, 36(1), 275-293.

## TR EFFECTS ON WELL-BEING

Sinha, S. (2013). *Living Longer, Living Well: Highlights and key recommendations*.

Retrieved from Ontario's Ministry of Health and Long Term Care website:

[http://www.health.gov.on.ca/en/common/ministry/publications/reports/seniors\\_strategy](http://www.health.gov.on.ca/en/common/ministry/publications/reports/seniors_strategy).

Shan, Y. (2013). Treatment of Alzheimer's disease. *Primary Health Care*, 23(6), 32-38.

Smith, E. (2008). Pitfalls and promises: The use of secondary data analysis in educational research. *British Journal of Educational Studies*. 56(3), 323-339.

DOI:10.1111/j.1467-8527.2008.00405.x.

Stewart-Brown, S., Tennant, A., Tennant, R., Platt, S., Parkinson, J., & Weich, S. (2009).

Internal construct validity of the Warwick-Edinburgh Mental Well-Being Scale

(WEMWBS): A Rasch analysis using data from the Scottish health population

survey. *Health and Quality of Life Outcomes*. 7, 1-8. DOI: 10.1186/1477-7525-7-15.

Stewart-Brown, S., & Janmohamed, K. (2008). User guide version 1. In J.Parkinson

(Ed.). *Warwick-Edinburgh Mental Well-Being Scale (WEMWBS)*. (pp.1-27).

Location: University of Warwick.

Tripathy, J.P. (2013). Secondary data analysis: Ethical issues and challenges. *Iranian*

*Journal of Public Health*, 42(12), 1478-1479.

Trugade, M. M., Fredrickson, B. L., Barrett, F. L. (2004). Psychological resilience and

positive emotion granularity: Examining the benefits of positive emotions on coping

and health. *Journal of Personality*, 72(6), 1161-1190.

## TR EFFECTS ON WELL-BEING

University of Victoria: Office of community-based research. (2011). *CBR & Partnerships*

[pamphlet]. University of Victoria: Author.

Watson, D., Clark, L.A., & Tellegan, A. (1988). Development and validation of brief measures of positive and negative affect: The PANAS scales. *Journal of*

*Personality and Social Psychology*, 54(6), 1063-1070.

Weytens, F., Luminet, O., Verhofstalt, L., & Mikolajczak, M. (2014). An integrative theory-driven positive emotion regulation intervention. *PLoS ONE*. 9(4): e95677.

DOI: 10.1371/journal.pone.0095677.

Wong, A. (2014). *National dementia research and prevention plan: Support for Caregivers*. Government of Canada: Minister of State (Seniors).

## TR EFFECTS ON WELL-BEING

*"This program made us want to exercise further in the week. It improved our physical, mental and emotional being."*

*Minds in Motion participating couple*

*"If I could change one thing about the Minds in Motion it would be... to make it full time"*

*Minds in Motion participant living with dementia*

*"The social activity portion of the program is excellent! I've seen my relative receive mental stimulation and positive encouragement, plus the interaction with other participants really helped build her self-esteem!"*

*Minds in Motion care partner*

*"He seems more cheerful now and I have more tenacity now to keep going on the journey."*

*Minds in Motion care partner*



#### Next session:

To sign up as a participant, volunteer with the program, or learn more, please contact:

Participating pairs will pay a minimal fee for participation in the full eight week program. Please enquire with the Society.

### Alzheimer Society

The Alzheimer Society offers **Help for Today** through our programs and services for people living with dementia and **Hope for Tomorrow...**® by funding research to find the cause and the cure.

\*Minds in Motion participants fill out a weekly assessment survey to help monitor the program's outcomes. Findings are used to further develop Ontario's Minds in Motion program.

*Société Alzheimer Society*

## Minds in Motion™

A physical activity and brain stimulation program for people with dementia and their care partners.

## Give your mind and body a boost!

Ontario

Ontario Trillium Foundation

Fondation Trillium de l'Ontario

ONTARIO BRAIN INSTITUTE

INSTITUT CANADIEN DU CERVEAU



Participant Registration

Name (first, last): \_\_\_\_\_

Gender: \_\_\_\_\_ Birth date (mm/dd/yyyy): \_\_\_\_\_

Address: \_\_\_\_\_

Phone (home): \_\_\_\_\_ Phone (cell): \_\_\_\_\_

Substitute decision maker name (first, last): *If not applicable, mark as N/A* \_\_\_\_\_

Substitute decision maker phone (option #1): *If not applicable, mark as N/A* \_\_\_\_\_

Substitute decision maker phone (option #2): *If not applicable, mark as N/A* \_\_\_\_\_

Emergency contact name (first, last): \_\_\_\_\_

Emergency contact phone (option #1): \_\_\_\_\_

Emergency contact phone (option #2): \_\_\_\_\_

Allergies:

*Please note if an epi-pen is kept on the person and, if so, the location* \_\_\_\_\_

Name of person they are attending with(first, last) \_\_\_\_\_

**Additional note worthy information** (e.g., uses a wheelchair, deaf in the left ear, communicates via sign language, should not leave unless picked up, Spanish speaking, etc.)



Appendix C

UNIVERSITY OF WATERLOO

Page 1 of 1

UNIVERSITY OF WATERLOO

OFFICE OF RESEARCH ETHICS

Notification of Ethics Clearance of Application to Conduct Research with Human Participants

Principal/Co-Investigator: Laura Middleton

Department: Kinesiology

ORE File #: 19803

Project Title: Evaluation of Minds in Motion

*This certificate provides confirmation the above project has been reviewed in accordance with the University of Waterloo's Guidelines for Research with Human Participants and the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans. This project has received ethics clearance through a University of Waterloo Research Ethics Committee.*

**Note 1:** *This ethics clearance is valid for one year from the date shown on the certificate and is renewable annually. Renewal is through completion and ethics clearance of the Annual Progress Report for Continuing Research (ORE Form 105).*

**Note 2:** *This project must be conducted according to the application description and revised materials for which ethics clearance has been granted. All subsequent modifications to the project also must receive prior ethics clearance (i.e., Request for Ethics Clearance of a Modification, ORE Form 104) through a University of Waterloo Research Ethics Committee and must not begin until notification has been received by the investigators.*

**Note 3:** *Researchers must submit a Progress Report on Continuing Human Research Projects (ORE Form 105) annually for all ongoing research projects or on the completion of the project. The Office of Research Ethics sends the ORE Form 105 for a project to the Principal Investigator or Faculty Supervisor for completion. If ethics clearance of an ongoing project is not renewed and consequently expires, the Office of Research Ethics may be obliged to notify Research Finance for their action in accordance with university and funding agency regulations.*

**Note 4:** *Any unanticipated event involving a participant that adversely affected the participant(s) must be reported immediately (i.e., within 1 business day of becoming aware of the event) to the ORE using ORE Form 106. Any unanticipated or unintentional changes which may impact the research protocol must be reported within seven days of the deviation to the ORE using ORE form 107.*

Maureen Nijmeling, PhD  
Chief Ethics Officer

OR  
Julie Joza, MPH  
Senior Manager, Research Ethics

OR  
Sacha Geer, PhD  
Manager, Research Ethics

April 29/14  
Date

+ one minor  
revision as  
outlined in  
email

Copyright © 2000-02 University of Waterloo

<http://iris.uwaterloo.ca/ethics/form101/ad/reports/certificateB1.asp?id=31327>

4/29/2014

Appendix D



Brock University  
Research Ethics Office  
Tel: 905-688-5550 ext. 3035  
Email: reb@brocku.ca

Bioscience Research Ethics Board

Certificate of Ethics Clearance for Human Participant Research

DATE:

4/5/2016

PRINCIPAL INVESTIGATOR:

LANE, Suzie - Recreation and Leisure Studies

FILE:

15-268 - LANE

TYPE:

Masters Thesis/Project

STUDENT:

Laura Rolph

SUPERVISOR:

Suzie Lane

TITLE:

Minds in Motion: Alzheimer Society of Ontario Pilot Project

**ETHICS CLEARANCE GRANTED**

Type of Clearance: NEW

Expiry Date: 4/28/2017

The Brock University Bioscience Research Ethics Board has reviewed the above named research proposal and considers the procedures, as described by the applicant, to conform to the University's ethical standards and the Tri-Council Policy Statement. Clearance granted from **4/5/2016** to **4/28/2017**.

The Tri-Council Policy Statement requires that ongoing research be monitored by, at a minimum, an annual report. Should your project extend beyond the expiry date, you are required to submit a Renewal form before 4/28/2017. Continued clearance is contingent on timely submission of reports.

To comply with the Tri-Council Policy Statement, you must also submit a final report upon completion of your project. All report forms can be found on the Research Ethics web page at <http://www.brocku.ca/research/policies-and-forms/research-forms>.

In addition, throughout your research, you must report promptly to the REB:

a)

Changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;

b)

All adverse and/or unanticipated experiences or events that may have real or potential unfavourable implications for participants;

c)

New information that may adversely affect the safety of the participants or the conduct of the study;

d)

Any changes in your source of funding or new funding to a previously unfunded project.

We wish you success with your research.

Approved:

Sandra Peters, Chair  
Bioscience Research Ethics Board

**Note:**

Brock University is accountable for the research carried out in its own jurisdiction or under its auspices and may refuse certain research even though the REB has found it ethically acceptable.

If research participants are in the care of a health facility, at a school, or other institution or community organization, it is the responsibility of the Principal Investigator to ensure that the ethical guidelines and clearance of those facilities or institutions are obtained and filed with the REB prior to the initiation of research at that site.



**Informed Consent**

Thank you for registering for Minds in Motion. We are very excited about your decision to take part in this exciting program! We do request, however, your understanding and cooperation in maintaining both your and our safety and health by reading and signing the following Informed Consent.

I, \_\_\_\_\_ (DOB: \_\_\_\_\_), **declare** that I intend to participate in Minds in Motion, a program of the Alzheimer Society of XXXX at XXXX. **I am aware** that the Minds in Motion program has a physical activity component and that the program, as a whole, is educational, recreational and social in nature. **I understand** that each person, myself included, has a different capacity for participating in the physical, recreational, educational and social activities offered during Minds in Motion. **I further understand** that while I will be encouraged to engage in the activities learned during Minds in Motion, in my home, I am not being forced to do so and **I acknowledge** that such home activities will be engaged in without supervision. **I assume** full responsibility during and after my participation, for my choices to engage in, use or apply at my risk, any portion of the information or instruction I receive.

**I understand** that part of the risk involved in undertaking any physical or recreational activity is relative to my own state of fitness or health (physical, mental or emotional) and the awareness, care and skill with which I conduct myself in that activity or program. **I acknowledge** that my choice to participate in Minds in Motion brings with it the assumption by me of those risks or results stemming from this choice and the fitness, health, awareness, care and skill that I possess and use. In addition, **I understand** that I am free to withdraw from, reduce or modify my involvement in any part of Minds in Motion and realize that I should do so upon recognition of any signs of light-headedness, fainting, chest discomfort, leg cramps, nausea and/or other symptoms.

**I further understand** that while the personnel leading Minds in Motion have skills and experience for which they were hired and they have received training specific to the delivery of Minds in Motion, these personnel may not be licensed, certified or registered instructors or professionals (e.g., Certified Fitness Instructors, Kinesiologists, etc.). **I accept** the fact that the skills and competencies of personnel will vary according to their training and experience and that no claim is made to offer assessment or treatment of any mental or physical disease or condition by those who are not fully licensed, certified or registered herein employed to provide such professional services.

**I acknowledge** that I have inquired about the nature of the physical and recreational activities offered during Minds in Motion. **I also recognize and acknowledge** that there may be certain risks involved in participating in Minds and Motion activities and **I voluntarily agree** to assume the full risk of any injuries, damages or losses that I may sustain as a result of participation. **I further agree** to waive and relinquish all claims I may have, as a result of participating, against Minds in Motion, including the Alzheimer Society employees, volunteers, students; the Alzheimer Society of Ontario; and the Alzheimer Society of XXXX (referred to as “parties”). **I fully release and forever discharge** the parties from any and all claims for injuries, damages, or losses that I may have or which may occur, or in any way be associated with Minds in Motion.



## Informed Consent

**I declare that I have read, understood and agreed to the contents of this INFORMED CONSENT AGREEMENT in its entirety and that by signing this, I am giving up legal rights and/or remedies which may**

## Participant

Witness

Date

Substitute Decision Maker

Witness

Date

(if applicable)

# Minds in Motion®

A physical activity and brain stimulation program for people with dementia and their care partners.

## Participant Consent to Participate in the Evaluation of Minds in Motion

The Alzheimer Society of Ontario, in partnership with Waterloo University and Brock University, will be evaluating the effectiveness of the Minds in Motion program. This includes both the physical activity and recreational portions of the program. The research team includes Laura Middleton from the University of Waterloo, Department of Kinesiology; and Suzie Lane and Laura Rolph from Brock University, Department of Recreation and Leisure Studies. Findings will be used for further development of the Minds in Motion program or other programs and services and may be published.

As a result of your participation in Minds in Motion, the Alzheimer Society hopes that you will:

- Maintain or improve your ability to move and perform tasks
- Increase the amount and intensity of physical activity that you do
- Increase your participation in community-based recreation
- Become more connected to your community
- Become more socially engaged
- Achieve an overall greater satisfaction with life
- Increase your knowledge of the benefits of physical activity and social interaction

The evaluation and research component of Minds in Motion includes asking you, the participant, to engage in an assessment of your physical abilities and to complete a questionnaire. You will be asked to complete these before the start of the program or during the first session of the eight week program. You will be asked to complete these again following completion of the program or during the final session of the eight week program. You will be asked to complete the assessment and questionnaire a final time six months following the end of the eight week program, if you are available and able to do so. Additionally, during each weekly session, you will be asked to identify your feelings immediately following the physical activity component of the program and again following completion of the recreational component of the program. This will be done by completing a weekly check-in tool.

Participation in the research portion of Minds in Motion is completely voluntary and will not affect your participation in Minds in Motion. You may choose to complete all assessments but not share the data with researchers. Or, you may choose to participate but may choose not to complete all assessment activities or answer all of the questions found within the questionnaires. Similarly, you may choose not to complete the weekly check-in. You will still be permitted to participate in Minds in Motion.

Your privacy will be protected. Your name will be replaced with an identification number before your data is sent to researchers, ensuring your identity remains anonymous. Your name will not be included in any evaluation or research report or any publication. The anonymized data that is sent to researchers will be kept at the University of Waterloo (BMH 1015) and at Brock University for up to 7 years.

We hope that you will help us by participating in the evaluation and research component of Minds in Motion. Your participation will help us improve this program to support persons with early to mid-stage dementia and their care partners. Additionally, by participating in the evaluation and research component of Minds in Motion, the Alzheimer Society and broader research team will have the opportunity to inform future programming and service delivery that can broadly impact the health and wellness of persons with early to mid-stage dementia and their care partners.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee. If you have any questions with regard to this research, including any comments or concerns resulting from your participation in this

TR EFFECTS ON WELL-BEING

study, you may contact Maureen Nummelin at the University of Waterloo Office of Research Ethics via email: [mnummelin@uwaterloo.ca](mailto:mnummelin@uwaterloo.ca) or via phone at (519)-888-4567.

YES, I agree to participate in the evaluation and research component of Minds in Motion by:

- ☐ taking part in the assessments of physical ability, the questionnaires, the weekly check-ins, and allowing this data to be shared with researchers for analysis, publications and presentations.
- ☐ completing the post-six month follow-up questionnaire and assessment of physical ability IF I am available and able to do so.

OR

- ☐ NO, I choose not to participate at this time.

Participant Name	Date
Participant Signature	
Substitute Decision Maker Name	Date
Substitute Decision Maker Signature	
Alzheimer Society Staff Name	Date
Alzheimer Society Signature	

## The Warwick-Edinburgh Mental Well-being Scale (WEMWBS)

Below are some statements about feelings and thoughts.

Please tick the box that best describes your experience of each over the last 2 weeks

STATEMENTS	None of the time	Rarely	Some of the time	Often	All of the time
I've been feeling optimistic about the future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been feeling useful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been feeling relaxed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been feeling interested in other people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've had energy to spare	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been dealing with problems well	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been thinking clearly	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been feeling good about myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been feeling close to other people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been feeling confident	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been able to make up my own mind about things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been feeling loved	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been interested in new things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been feeling cheerful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Warwick-Edinburgh Mental Well-Being Scale (WEMWBS)

© NHS Health Scotland, University of Warwick and University of Edinburgh, 2006, all rights reserved.

TR EFFECTS ON WELL-BEING      Appendix H

**Minds in Motion®**

**Participant self assessment questionnaire**

**Pre-program assessment**

**Identifier**

**Date:**

**Code:** \_\_\_\_\_

1. Why did you join up for Minds in Motion?

2. In the last eight weeks:

a.	I have participated in physical activities.....	Less than once per week	Once per week	Twice per week	Three times per week	More than three times per week
b.	Each time I participate, I am active for.....	Less than 15 minutes	15-30 minutes	30 minutes to 1 hour	More than 1 hour	
c.	And the intensity of my physical activity is...	<b>Low</b> (I don't breath any harder and my chest doesn't pound)		<b>Moderate</b> (I breath a little harder and my heart beats faster)		<b>High</b> (I'm out of breath and my heart beats very fast)

3. For each statement, please tick the box that best describes how you feel.

		<b>Not Confident</b>	<b>Somewhat Confident</b>	<b>Confident</b>
a.	I feel I could exercise three times per week, for 20 minutes each time, even if I had to exercise alone.			
b.	I feel I could exercise three times per week, for 20 minutes each time, even if I felt tired.			
c.	I feel I could exercise three times per week, for 20 minutes each time, even if I felt stressed.			
d.	I feel I could exercise three times per week, for 20 minutes each time, even if I felt depressed.			



## TR EFFECTS ON WELL-BEING

4. Please rate your level of understanding of the following:

		Little Understanding	Good Understanding	Extensive Understanding
a.	The way that physical activity can affect my health.			
b.	The way that socializing can affect my health.			
c.	The way that participating in enjoyable and meaningful activities can affect my health.			

5. Below are some statements about feelings and thoughts. Please tick the box that best describes your experience of each **over the last two weeks**.

	Statements	None of the time	Rarely	Some of the time	Often	All of the time
a.	I've been feeling optimistic about the future.					
b.	I've been feeling useful.					
c.	I've been feeling relaxed.					
d.	I've been feeling interested in other people.					
e.	I've had energy to spare.					
f.	I've been dealing with problems well.					
g.	I've been thinking clearly.					
h.	I've been feeling good about myself.					
i.	I've had a good relationship with other people.					
j.	I've been feeling confident.					
k.	I've been able to make up my own mind about things.					
l.	I've been feeling loved.					
m.	I've been interested in new things.					
n.	I've been feeling cheerful.					

## TR EFFECTS ON WELL-BEING

## Appendix I

**Minds in Motion®****Participant self assessment questionnaire****Post-program assessment****Identifier****Code:** \_\_\_\_\_**Date:** \_\_\_\_\_**1. In the last eight weeks:**

a.	I have participated in physical activities.....	Less than once per week <input type="checkbox"/>	Once per week <input type="checkbox"/>	Twice per week <input type="checkbox"/>	Three times per week <input type="checkbox"/>	More than three times per week <input type="checkbox"/>
b.	Each time I participate, I am active for.....	Less than 15 minutes <input type="checkbox"/>	15-30 minutes <input type="checkbox"/>	30 minutes to 1 hour <input type="checkbox"/>	More than 1 hour <input type="checkbox"/>	
c.	And the intensity of my physical activity is...	<b>Low</b> (I don't breath any harder and my chest doesn't pound) <input type="checkbox"/>	<b>Moderate</b> (I breath a little harder and my heart beats faster) <input type="checkbox"/>	<b>High</b> (I'm out of breath and my heart beats very fast) <input type="checkbox"/>		

**2. For each statement, please tick the box that best describes how you feel.**

		<b>Not Confident</b>	<b>Somewhat Confident</b>	<b>Confident</b>
<input type="checkbox"/>	I feel I could exercise three times per week, for 20 minutes each time, even if I had to exercise alone.			
<input type="checkbox"/>	I feel I could exercise three times per week, for 20 minutes each time, even if I felt tired.			
<input type="checkbox"/>	I feel I could exercise three times per week, for 20 minutes each time, even if I felt stressed.			
<input type="checkbox"/>	I feel I could exercise three times per week, for 20 minutes each time, even if I felt depressed.			

**3. In the last eight weeks, I have participated in:**

- No social or recreation activities in the community aside from Minds in Motion
- 1 social or recreational activity in the community, in addition to Minds and Motion
- 2 social or recreational activities in the community, in addition to Minds in Motion
- 3 social or more recreational activities in the community, in addition to Minds in Motion

**4. At least one social or recreational activity I participated in, in the last eight weeks, has been at the same Centre where Minds in Motion took place.**

- Yes
- No
- Not applicable – I have not participated in any additional activities

**5. In the last eight weeks, I have started to talk to or do more with family and/or friends.**

- Yes
- No

## TR EFFECTS ON WELL-BEING

6. I have developed a friendship with at least one other person participating in Minds in Motion that I expect to see socially outside of the program.

- Yes
- No

7. Please rate your level of understanding of the following:

		Little Understanding	Good Understanding	Extensive Understanding
a.	The way that physical activity can affect my health.			
b.	The way that socializing can affect my health.			
c.	The way that participating in enjoyable and meaningful activities can affect my health.			

8. Below are some statements about feelings and thoughts. Please tick the box that best describes your experience of each **over the last two weeks**.

	Statements	None of the time	Rarely	Some of the time	Often	All of the time
a.	I've been feeling optimistic about the future.					
b.	I've been feeling useful.					
c.	I've been feeling relaxed.					
d.	I've been feeling interested in other people.					
e.	I've had energy to spare.					
f.	I've been dealing with problems well.					
g.	I've been thinking clearly.					
h.	I've been feeling good about myself.					
i.	I've had a good relationship with other people.					
j.	I've been feeling confident.					
k.	I've been able to make up my own mind about things.					
l.	I've been feeling loved.					
m.	I've been interested in new things.					
n.	I've been feeling cheerful.					

## TR EFFECTS ON WELL-BEING

**Mind in Motion®**  
**For completion by volunteers, students and program delivery staff**

<b>PRE-program participation assessment</b>					
<b>5 character personal identifier</b>					

1. Please identify your role with Minds in Motion:
  - ☐ Minds in Motion Coordinator
  - ☐ Physical activity program leader employed by the partnering recreation centre, Older Adult
  - ☐ Centre or similar community-based multi-service centre
  - ☐ Physical activity program leader employed by the Alzheimer Society
  - ☐ Volunteer (including high school and college or university students who are volunteering their time)
  - ☐ Post-secondary student placement (college or university students using this placement as formal hours toward their diploma or degree, etc.)
  - ☐ Other: \_\_\_\_\_
  
2. Please rate your amount of experience working with the following populations, with 1 being no experience and 5 being extensive experience.

		N o e x p e r i e n c e	V e r y l i m i t e d e x p e r i e n c e	S o m e m p e r i e n c e	A f f i r m b a s i c e x p e r i e n c e	E x t e n s i v e E x p e r i e n c e
		1	2	3	4	5
a.	Older adults (55 - 64 years)					
b.	Seniors (65 years +)					
c.	Persons with Alzheimer's disease or other dementias					
d.	Care partners of persons with Alzheimer's disease or other dementias					
e.	Persons with complex health conditions					
f.	Persons who have impaired mobility					
g.	Persons who have a cognitive impairment (e.g., confusion, difficulties with concentration, memory, reading, writing, language, reasoning, etc.)					
h.	Persons who face exclusion from mainstream activities due to something they are living with (e.g., illness, disability, etc.)					

## TR EFFECTS ON WELL-BEING

3. Please rate your skill level working with the following populations, with 1 being no skill and 5 being extensive skill:

		N o s k i l	V e r y l i m i t e d s k i l	S o m e l l o f s k i l	A f f i r m s k i l	E x t e n s i v e s k i l
		1	2	3	4	5
a.	Older adults (55 - 64 years)					
b.	Seniors (65 years +)					
c.	Persons with Alzheimer's disease or other dementias					
d.	Care partners of persons with Alzheimer's disease or other dementias					
e.	Persons with complex health conditions					
f.	Persons who have impaired mobility					
g.	Persons who have a cognitive impairment (e.g., confusion, difficulties with concentration, memory, reading, writing, language, reasoning, etc.)					
h.	Persons who face exclusion from mainstream activities due to something they are living with (e.g., illness, disability, etc.)					

4. Please rate your level of knowledge in the following areas, with 1 being no knowledge and 5 being extensive knowledge:

		N o k n o w l e d g e	V e r y l i m i t e d k n o w l e d g e	S o m e w h a t k n o w l e d g e	A f f i r m k n o w l e d g e	E x t e n s i v e k n o w l e d g e
a.	The signs and symptoms associated with the earlier stages of Alzheimer's disease and other dementias.					
b.	The impact that dementia has on the physical health of a person living with dementia, when they are in the earlier stages of the					

## TR EFFECTS ON WELL-BEING

	disease.						
c.	The impact that dementia has on the emotional health of a person living with dementia, when they are in the earlier stages of the disease.						
d.	The impact that a diagnosis of dementia has on the physical health of loved ones of persons with dementia, when the person with dementia is in the earlier stages of the disease.						
e.	The impact that a diagnosis of dementia has on the emotional health of loved ones of persons with dementia, when the person with dementia is in the earlier stages of the disease.						
f.	The meaning of 'Therapeutic Recreation'.						
g.	The difference between Therapeutic Recreation and recreation.						
h.	The impact of participation in Therapeutic Recreation, on a person's overall health and wellness.						
i.	The meaning of 'Recreation and Leisure'.						
j.	The impact of participation in recreation and leisure activities, on a person's overall health and wellness.						
k.	The sort of activities that are considered to be 'physical activity'.						
l.	The impact of physical activity in a person's overall health and wellness.						

5. When meeting someone for the first time, who I know is in the earlier stages of dementia, I feel:
- ☐ **Scared** and would rather avoid meeting him/her by myself, if at all possible; would prefer to first observe how the person with dementia acts with other people, before I engage with him/her
  - ☐ **Nervous and unsure** of how to interact with that person; would prefer to have someone else with me that is familiar with the person and/or has experience working with people with dementia
  - ☐ **No different** than I do meeting anyone for the first time; will use my knowledge and skills to engage with that person to ensure the interaction is a positive one
6. I have plans to:
- ☐ Pursue a career working with older adults
  - ☐ Pursue a career working with persons with dementia
  - ☐ Pursue a career working in the health sector, but I am unsure of focus at this time
  - ☐ Pursue a career working in the helping profession, but am unsure of focus at this time
  - ☐ Pursue a career in a field totally unrelated to anything associated with Minds in Motion – I simply want to contribute my time because this is important to me
  - ☐ Continue with my current job as is – Minds in Motion is simply another component of what I do
  - ☐ Concentrate more of my time, in my current role, to working with older adults
  - ☐ Concentrate more of my time, in my current role, to working with persons with dementia
  - ☐ Change my career focus entirely, to work with older adults
  - ☐ Change my career focus entirely, to work with persons with dementia
  - ☐ Volunteer my time with Minds in Motion/the Alzheimer Society – I am no longer working
  - ☐ Other: \_\_\_\_\_

Pre-assessment		Post-assessment	
<b>Students/Volunteers</b>	Prior to initial training and program orientation	<b>Students/Volunteers</b>	Upon completion of each 8 week program
<b>Delivery staff</b>	Prior to initial training and program orientation	<b>Delivery staff</b>	By February 28, 2015 By March 15, 2016